

THE SAVVY CONSUMER'S GUIDE TO HEARING LOSS

BY KAREN ROCKOW, PhD

THE IMPACT OF DEAFNESS WHERE TO TURN FOR HELP HELPING
YOURSELF COMMUNICATION SKILLS ASSISTIVE TECHNOLOGY
COMMUNICATION OPTIONS AUXILIARY SERVICES REAL LIFE COPING

DEVELOPED UNDER A CONTRACT FROM THE MASSACHUSETTS
COMMISSION FOR THE DEAF AND HARD OF HEARING

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The Massachusetts Commission for the Deaf and Hard of Hearing is an agency of the Commonwealth of Massachusetts under the Executive Office of Human Services.

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The Agency

The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) is the central agency in state government in Massachusetts providing information, referral, public education, and many specialized services for Deaf, oral deaf, late-deafened and hard of hearing people. The MCDHH sought the development of this Guide in recognition of the need for earlier and better information about acquired hearing loss for individuals who lose their hearing, for the professionals who work with them, and for their family, friends and colleagues.

For information about obtaining more copies of this book or to access the services of MCDHH information sheets on the website contact:

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Speak with anyone who has lost his or her hearing after developing spoken language and you will hear a constant refrain: “If only I had known about the Association of Late-Deafened Adults and the Hearing Loss Association of America. If only I’d known where to turn to learn how to speechread or to learn sign language. If only I’d known there was such a thing as CART service....”

This book has been written as an antidote to the “if onlys.”

Its success has been extremely gratifying. We estimate that there are over 40,000 copies of the older editions (**A Guide for People Who Become Deaf or Severely Hard of Hearing; A Late-Deafened Consumer’s Perspective**) in print, making it one of the most widely distributed books on hearing loss in existence. My collaboration with the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) has been a very happy one. I’m unaware of such a volume produced by any other state agency for the deaf and hard of hearing.

There have been so many advances in hearing loss technology that an update is long overdue. I am immensely grateful to Commissioner Heidi Reed for making this revision possible and for her continuing support of the book. Similarly, I would like to thank Jonathan O’Dell, head of the Communication Access, Training and Technology Services (CATTS) Department at MCDHH and manager of this project, for his many contributions to this edition, his support, wit, and patience. Deputy Commissioner Patricia Ford read the manuscript and commented on it. Carole Rossick, technical guru of the CATTS Dept., generously shared her expertise. Karin Williams and Jon O’Dell shared their stories with us, joining the incomparable Helen Fleming and Annette Posell of the National Center for Accessible Media. Jane Sokol Shulman of MCDHH handled some very hairy contract details and lent support, encouragement, and many quotable quotes. Bob MacPherson, owner of the bhNEWS listserve, Emilie Quast, owner of Beyond Hearing, former colleague and audiologist Brad Ingrao, friends Eve Golden, Kathleen Tinkel, Sharon Saronson, and Louise Salant lent support, information, and editorial suggestions. Much of what I know about hearing loss stems from my association with Geoff Plant of the Hearing Rehabilitation Foundation, with whom I’ve held many conversations over the years as research subject, colleague, and friend.

Finally, I want to thank Laura Meier, my successor as president of the Boston chapter of the Hearing Loss Association of America. She put in countless hours researching and updating information, correcting formatting, and discussing organization. She also reminded this very absentminded author of things to do, sections to revise, and a thousand other small details that made this revision possible.

FROM MCDHH

In our work through the last twenty years at the MCDHH, people who have become deaf or severely hard of hearing, nationally and in Massachusetts, have impressed upon us the need for clear information on acquired hearing loss... distinct from information on deafness at birth and in the very early years of life. The information is needed by consumers themselves who have become deaf and by the professionals whom they meet when hearing loss occurs. In addition to the “if only I had known” refrain from individuals who have become deaf or severely hard of hearing we hear:

- * Too many professionals who are supposed to be able to help late-deafened or very severely hard of hearing people just don't understand what it really means to become deaf. They can't and don't give us the information, support, contacts and even appropriate communication access that we need in order to deal with hearing loss. They too often just don't understand “how it really is” and “what we really need”.

These two refrains, both loud and clear, have resulted in this Guide which will be made available to people who become deaf or severely hard of hearing, the professionals who work with them, and their family, friends and colleagues.

MCDHH Management Team

*In memory of
Raymond W. Reed, PhD,
a gentle soul whose
own hearing loss, spirit,
humor, and commitment to
assisting others inspired many in
achieving accessible
communication of
their own.*

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INTRODUCTION

Acquired deafness influences every aspect of our lives, and it can be devastating to those who grew up in the hearing world. By seriously interfering with communication, it affects our feelings of identity, of competence, our family and community relationships and our careers. It demands that we make major adjustments in our lives and how we interact with others and the world, that we re-evaluate our very existences and hopes. As Bena Shuster writes in her book, *Life After Deafness*, "On July 17, 1986, I became deafened overnight, due to an unknown virus. When I first became deafened, I had never met a deaf person and knew absolutely nothing about deafness.... No one told me how to live with my deafness.... I thought my life was over."

As Bena learned, and as we hope to demonstrate in this book, hearing loss is not the end of the world. It may seem odd to say this, but if you must lose your hearing, this is a better time to do so than ever before. The world is becoming more and more accessible, tolerance for diversity is growing, the computer revolution and miniaturization have provided us with multi-faceted tools for communication and environmental awareness. Science has provided us with assistive devices, cochlear implants, and hearing aids; medical research on the causes and possible cures for acquired hearing loss is continuing on many fronts. If you choose to do so - and most people with acquired hearing loss do - you can remain in the hearing world and live a full and happy life.

This book is intended as an "adjustment manual," a resource guide for people who have lost all or most of their hearing during their teenage or adult years. It presents information about:

- **The impact of hearing loss**
- **Available resources and services**
- **Communication options**
- **Assistive technology**
- **Coping strategies**
- **Connecting with other people who have become deaf or severely hard of hearing**

In short, this book seeks to help late-deafened people learn to become deaf or hard of hearing gracefully. We also hope that it will be widely distributed among service providers — audiologists, primary care physicians, and social workers — and will help them to understand and give knowledgeable advice to their deafened clients.

Some of the issues we touch are emotionally charged and have in the past provoked vehement controversy. I've tried to present information in a clear, non-judgmental way so that this book will help people make their own informed decisions. Hearing loss is all about decisions. No one is born knowing how to cope with hearing loss. We need information, we need support from others who have traveled this way before, and we need to learn how to live by a new set of rules.

How to Use the Guide

You can pick up this guide and start reading at any section that interests you. We've divided the book into eleven chapters. In addition, we've gathered all the references in an appendix at the end, arranged under section headings.

Chapter 1: The Impact of Deafness

Deals with the effects of deafness on people's lives. If you're newly deafened, it will tell you what to expect and discuss some of the emotions you may have.

Chapter 2: Where to Turn for Help

Lists organizations and agencies that you can turn to for information and support, as well as information about medical procedures.

Chapter 3: Communication Options

Discusses options you may wish to investigate for your communication needs.

Chapter 4: Communication Skills

Talks about ways to make communication easier for yourself.

Chapter 5: Hearing Aids and Cochlear Implants

Discusses electronic ways to improve your hearing and the impact of these on relationships.

Chapter 6: Assistive Technology

Introduces assistive technology that is available to use with and without hearing aids and cochlear implants.

Chapter 7: Auxiliary Services

Discusses auxiliary services, such as interpreters and CART (Communication Access Realtime Translation), that you may want to use.

Chapter 8: Helping Yourself

Discusses methods you can use to optimize your communication skills and make life with hearing loss easier.

Chapter 9: Real Life Coping

Draws on the experiences of many late-deafened adults in dealing with everyday situations. It also deals with your rights under the Americans with Disabilities Act (ADA).

Chapter 10: Emergency Preparedness

Helps you understand what you can and cannot expect from your local government in the event of an emergency; helps you plan for the worst.

Chapter 11: Final Words

Lists books and periodicals for further reading.

Appendix: References

Lists further resources for each section.

Remember that it's impossible for a book of this sort to remain completely current for long. Technology changes very rapidly. Organizations, contacts, Web pages, and the like come and go. If you find any of these glitches or think we should include additional information in a subsequent edition or update, please contact me at karen@karenrockow.com or write the Massachusetts Commission for the Deaf and Hard of Hearing at 150 Mt. Vernon Street, Suite 550, Dorchester, MA 02125. We also welcome any other comments.

Terms We'll Use in the Guide

What's the difference between hard of hearing and deaf? Between Deaf (with a capital D) and deaf (with a lowercase D)? Between late-deafened and Deaf? You can define these terms in many ways.

Terminology has sometimes been a source of confusion and even conflict among people with hearing loss, and there is a great deal of overlap in the use of the words. “When I use a word, it means just what I choose it to mean,” said Humpty Dumpty. Here are the meanings I’ll use in this book:

hard of hearing (HoH): Describes people who still have some useful hearing and can understand spoken language through hearing in some situations, with or without amplification. Most HoH people can still use the telephone and make use of hearing aids and assistive devices. The degree of hearing loss can vary considerably, from mild to profound.

deaf: People who are audiotically deaf have little or no residual hearing. They may use sign language or speech reading, and hearing aids may be used both for environmental awareness and for what little additional benefit they may provide in making speech intelligible. Those who use spoken English as their preferred form of communication are called oral deaf.

Deaf: People who think of themselves as members of the Deaf community, a cultural and linguistic minority for whom American Sign Language (ASL) is the preferred form of communication. Although the degree of hearing loss of members of the Deaf community varies considerably, the common denominator is that most Deaf people lost their hearing before the acquisition of spoken language (they are sometimes said to be pre-lingually deaf), and view hearing loss not as a medical condition that needs to be corrected, but as a cultural distinction.

late-deafened or deafened: Describes people who lost all or most of their hearing during or after the teen years (post-lingually, since they had already learned to use spoken language), either suddenly or progressively. Most cannot use the telephone and need sign language or speech reading to understand conversation. Sometimes called adventitiously deaf.

Pre-lingual: Before the acquisition of language. Describes people who are deaf from birth.

Post-lingual: After the acquisition of language. Describes people who are deafened after they have learned at least the basics of speech.

As we’ll discuss later, many people who think of themselves as late-

deafened sometimes introduce themselves as being hard of hearing. And many people with severe to profound hearing losses prefer to call themselves hard of hearing. This book is specifically written for late-deafened individuals, and addresses their specific and urgent problems. At the same time, it should be of interest to others with lesser hearing losses, as well as to hearing friends and caregivers who wish to understand more about the experience of losing one's hearing after having grown up as a hearing person.

Acronyms We'll Use

ADA	Americans With Disabilities Act
ALD	Assistive Listening Device (for personal use)
ALS	Assistive Listening System (for multiple users or large area coverage)
ASL	American Sign Language
CAN	Computer Aided Notetaking
CART	Communication Access Realtime Translation
CC	Closed Captions
OC	Open Captioned
DAI	Direct Audio Input
DHILS	Deaf and Hard of Hearing Independent Living Services
MCDHH	Massachusetts Commission for the Deaf and Hard of Hearing
MRC	Massachusetts Rehabilitation Commission
RCD	Rehabilitation Counselor for the Deaf
TRS	Telecommunications Relay Service
VP	Video Phone
TTY	Text Telephone

About the Author

I first diagnosed my own hearing loss as a child. One day, I realized that the ticking of my noisy watch no longer bothered me when I held it out on one side. I cried a little, but didn't tell anyone, and promptly forgot about it for five years. By the time my hearing loss was officially diagnosed at age 15, while I was a freshman in college, it was already far advanced. At the time, it was a typical binaural (both ears) sensorineural loss, ranging from moderate at the lower frequencies to severe to profound at the higher ones. Typical, too, was the lack of rapport that the specialists I saw had with their patients — one referred me for speech therapy (which many late-deafened people do need, but which I didn't) and another whipped out a temporal bone bank donation form. Nor was there any mention of assistive devices that could have been helpful to me. This has, I hope, changed over the years, but I'm still amazed at how little information newly diagnosed, late-deafened adults receive.

After giving a borrowed hearing aid a two-minute trial using a makeshift earmold, I forgot about my hearing loss for another five years. I entered a lengthy period of denial, and refused to consider wearing a hearing aid until I was well into graduate school. Even then, I wore the aid only sporadically, relying instead on my lipreading skills. When my backpack, with the aid inside, was stolen a few years later, I didn't replace it for several years. It would be years before I accepted my hearing loss and began to wear two aids during all my waking hours. Recently, I asked an old friend from Harvard, with whom I used to drive to New York on weekends, if she had noticed my hearing loss when we met. "Oh yes," she replied. "I couldn't talk to you at all in the car while you were driving because you always turned to face me so you could lipread. Since I used to sit in the back seat, you scared me half out of my wits."

I went through the same emotional trauma when it became obvious — to everyone but me — that I couldn't handle voice telephone calls reliably. It took years before I got a TTY and used it almost exclusively for my telephone conversations. (In Chapter 6, we'll discuss these keyboard-equipped devices with small screens on which you can type and read messages via the phone.) I went through yet another period of resistance before being able to call myself "deaf" comfortably.

In 2003, having reached the point where my hearing aids gave me little benefit, I finally broke down and received a cochlear implant in my right ear. It was a humbling experience. For the first time in my life, I wasn't the "quick learner" I'd always been in the past. For another, I finally realized just how much I'd been missing over the years of my progressive loss. The implant has made a huge difference in my life. I'm able to use the telephone for many calls, though I still retreat to the TTY for important business calls. This I attribute mainly to laziness in practicing phone calls on my part, as well as a lack of confidence in my own abilities. Nor am I yet able to enjoy music as I once did. Again, having been unable to enjoy music for so many years, I've put little time into learning how to listen to it, though piano music seems to give me the most pleasure.

My story is unusual only in the fact that I was able to function well academically and socially with a severe to profound hearing loss for so long. For several years during grad school, I taught and even worked at the squash courts, where my main task was to take court reservations over a telephone that lacked any amplification. Somehow, I managed without any great trauma or frustration; I've always been able to make the most of the sounds I'm able to hear. Eventually, my loss reached the point where even I had to admit that I needed to learn more about available technology and coping strategies. I've been very fortunate to meet many people who have taken the time to help me and give me support.

Like many people with profound hearing losses, I've had to change my personal interests and career objectives several times: setting aside the violin, which I'd played since elementary school, changing majors in college, abandoning my goal of doing folklore fieldwork, and realizing that secondary school teaching was not the best career choice for me. I live alone with my dog and now run two businesses from my home office. After years of denial and researching solutions to my communications problems, I've made peace with my hearing loss.

Don't ever let anyone tell you that adapting to deafness is easy. It involves considerable upheaval, learning, and teaching. But it's a challenge that can be met, and the rewards in new interests, friendships, and increased self-awareness can be deeply satisfying.

1. THE IMPACT OF DEAFNESS

■ Overview

Deafness affects every facet of one's life. Although most people who lose their hearing experience similar emotions and difficulties, each of us responds in a unique way. In this chapter, we'll look at the stories of some late-deafened people, discuss the emotional impact of deafness, and look at the way deafness can affect different areas of our lives.

■ Causes of Late-Deafness

Deafness later in life can have many causes. Among the more common ones are:

- **exposure to loud noise**
- **aging (presbycusis)**
- **meningitis**
- **accidents, trauma**
- **virus**
- **Meniere's disease**
- **tumors of the acoustic nerve**
(*neurofibromatosis type II and acoustic neuromas*)

In many cases, doctors cannot determine the cause. See a doctor as quickly as possible if you experience:

- **a sudden drop in hearing**
- **unexpected dizziness (vertigo)**
- **drainage from the ear**
- **significant pain in the ear or head**

■ The Meetingplace

In this section, we introduce a few late-deafened adults who are "making it in Massachusetts," as a former governor used to say. For some of you, it may be one of the first times you've met people who are late-deafened. The people we profile here aren't intended to be standards by which you should measure yourself. They're simply interesting folk who have faced deafness and built useful and rewarding lives.

Helen Fleming

Wherever she goes, this white-haired, animated woman collects a crowd of friends and admirers. Helen Fleming has been a key figure on the Massachusetts hard of hearing scene for many years. Her efforts on behalf of people with hearing loss have been recognized by the Boston Guild for the Hard of Hearing, Self Help for Hard of Hearing People (SHHH, now the Hearing Loss Association of America, HLAA), the Independent Living Center (ILC) of the North Shore and Cape Ann, and by Channel 6 (the Independent Spirit Award). She has served on the Board of Directors of the Boston Guild for the Hard of Hearing and the ILC of the North Shore, and on the Statewide Advisory Council (SAC) for MCDHH. Along the way, she founded the North of Boston Self Help for Hard of Hearing People (SHHH) Group and spent six years as state SHHH coordinator.

Helen's hearing loss was first diagnosed when she was a sophomore at Regis College, where she received a B.A. in English. "I had absolutely no idea the impact that this hearing loss was going to have on my life. I think that if I had been able to see down the road, to see some of the traumatic experiences that I have had, there is no way in God's world that I would have had the courage or the nerve to go on and do the things that I did."

Her first hearing aid came by way of a cookie boxtop that she mailed into a contest. She actually won a go-kart, but the company let her take the money instead, and she bought a hearing aid.

She went on to receive a master's degree in education from Salem State College. "I still thought there was nothing in the world wrong with me," she recalls. "I kept thinking: There is nothing in this world that I can't do if I make up my mind about it... I think that the first time I began to acknowledge that I was having trouble was when I was labeled — that's why I don't like labels. I think labels hurt people. When they said, 'she's hearing-impaired.' Impaired? Like there was something faulty. You know, the package isn't right, send it back."

She taught school for 40 years. During the final 20 years, she taught remedial reading. "And that was a real blessing for me. I only had one to five students at a time. That way, I was able to cover up." She was terrified that the parents of her students would find out about her hearing loss. She was even afraid to ask for a personal day because "they would think, oh, she's not capable of doing the job." Finally, though, she applied for a personal day so she could go to the annual

luncheon of the Boston Guild for the Hard of Hearing to hear Rocky Stone, founder of Self Help for Hard of Hearing People. "He gave me so much to think about that day, I could not believe that a man who was deaf or that had to struggle in the hearing world could be so upbeat. And when I confronted him about that, he said, 'Aren't you upbeat?' I said...if I had the money, I'd buy a deserted island in the middle of the Pacific Ocean and I'd set up a tent and stay there. He asked why. I said so that I wouldn't have to listen to people... I didn't mind talking to them. It's the listening that bothers me. He then said, 'No, no, no.' That was not a luxury any of us could have in this world. Like it or not, we had to listen."

When her husband died 25 years ago, it was like losing her hearing all over again because he had been so supportive. "I was an angry, angry person," Helen recalls. "And I didn't know what the heck I was angry about. I thought I was angry at my family because they wouldn't cooperate with what I needed. How could they know what I needed when I didn't know that myself? And that's how my involvement with Self Help for Hard of Hearing taught me how to cope. It taught me how to modify aggressiveness to assertiveness. It taught me how to manage stress. I'm still working on the stress part."

Helen received her first cochlear implant in 1999. "I found I still needed to read lips, however the fact that I could hear birds chirping, the ringing of the telephone and doorbell, sirens from ambulances, fire trucks and police cars was music to my ears. I could finally drive with both eyes on the road instead of one on the road and one on the rear view mirror." She feels fortunate that she was implanted at the Massachusetts Eye and Ear Infirmary (MEEI) because they spent so much time with her on aural rehabilitation.

Five and a half years later, in late December, her implant "went kaput." Thinking it was the external element, she underwent three days of testing only to discover that for some unknown reason, the implant had failed. When she asked for a loaner, she was told that no hearing aid on the market could help her. "There was nothing left to do but grin and bear it." During the family get-together at Christmas, one of her grandsons told her it was just like old times. I spent four months with no hearing at all and it was one of the worst experiences in my life. I had become totally spoiled. Having had hearing for five and a half years, I was desolate." She was re-implanted in the same ear in March 2005. A month later, she was hooked up. This time, she did not need to spend as much time in aural rehabilitation.

"I am still alive and well and hearing as well as I did with the first implant. Was it worth it? Definitely. If this one ever goes on the fritz, I'll have it done again, only this time in my right ear," she reports.

"So from the individual who thought there was nothing left for her to do, who was afraid to be in a crowd, afraid to get up in front of a microphone because she was going to make a mistake, this individual now feels that she still has plenty of miles left on her engine, but she has miles to go before she sleeps. And I hope I will be able to keep going as an advocate for the rights of hard of hearing people."

Jonathan O'Dell

Jonathan O'Dell, the project manager for this book, has led a varied existence, both geographically and in the matter of hearing loss. Born in Jerusalem, Israel, to an Austrian chemist mother and American father who was at the time a part-time archeologist, editor, and basketball teacher, he began life with perfect hearing. He moved to Austria at the age of three, where his parents went their separate ways. His father insisted that he be educated in English, but he spoke German at home with his mother and her parents and considers the latter his "first language" because he spoke it for the majority of his formative years. He did not learn to sign until he was 26 years old.

Mumps at age four left him with decreased hearing; his grandparents noted that he was straining to hear music and sitting far too close to the radio, which was turned to high volume. A few years later, bouts with German measles and meningitis destroyed most of his remaining hearing. Although his memory of that period is fuzzy, he remembers "with a clarity that amazes me" the last night he could still hear. He recalls the doctor's cold stethoscope on his chest while he craned his neck to watch the silent horror film classic, "Nosferatu." After he recovered and found himself unable to hear with no explanation of what had happened, he became angry and withdrawn and started getting into fights when he was taunted. His grandmother was ill and his working mother couldn't handle her angry child, so he went to live with his father across town. After enduring several months of "charlatan cures," his father flew him to Indiana University for testing. There, he was diagnosed as having a severe sensorineural hearing loss with accompanying virtual loss of any sense of balance.

At age 10, he began to attend an oral school for the deaf and hard of hearing in Vienna and faced the first of many difficult years in his educational career. Until then, his formal education had been in English, so he had to learn written German under the guidance of two teachers who heaped on extra work. At the time, he hated them, but within two years he was at the top of his class, the pride of the school. After completing school, there was literally no place for him to go in Austria. His father, insisting that he was destined for more than vocational school, enrolled him at Dover College, a private boarding school in England favored by international students. So off he went to the bustling port city of Dover, Kent, England, where as the only student in the school with a hearing loss, he was terribly unhappy. Taunted by classmates, picked on by seniors because of his hearing loss, and humiliated academically, he stuck it out, with the help of an understanding Housemaster and some very good friends. He eventually found some sort of balance, managed to pass his "A" level exams, and obtained a diploma in linguistics. During his stay there, his mother had remarried and moved to Germany and his father and stepmother had moved to Nairobi, Kenya. He traveled a lot, and was sometimes brought close to tears by seatmates who tried to talk with him during the long flights to Africa, ashamed to admit that he was "different."

"One day," he relates, "I just became really, really angry at myself. I decided that I was not going to live like this any more.... I marched to the barber, had my hair cut short so my hearing aids were revealed, and the next time I sat down on a plane, I initiated contact by telling my seat neighbor that I had a hearing loss.... As clichéd as it sounds, that decision changed my life."

After Dover, it was off to America, quite unwillingly, to attend college in Wisconsin at his father's behest. Thrust from a bustling European port town to a rural Midwestern community, his four years there were disastrous. His hearing was worsening, he couldn't understand anyone on the telephone, and there were no support services for hard of hearing and deaf students in those times before the passage of the Americans with Disabilities Act (ADA). After four years of majoring in social life, he was dismissed for academic reasons. He went to work, met and fell in love with a woman from Massachusetts and moved there. "By the tremendous kindness of this woman's family and the incredible luck that one of their neighbors' daughters was an RCD (Rehabilitation Counselor for the Deaf)

at MRC (the MA Rehabilitation Commission), I was introduced to MRC and found my first professional job as an Independent Skills Trainer.” Shortly afterward, he was promoted to program coordinator at the Southeast Center for Independent Living, and after another three years, he went to work at MCDHH. There, he met his wife Kristin. Knowing that his academic record was a source of embarrassment, she encouraged him to enroll in the Division of Continuing Education at Harvard. He spent the next three years taking classes there, using a CART provider (see Chapter 7) supplied by the university in each class. He graduated with his Bachelor’s degree in 2000 and a Dean’s List Certificate of Academic Achievement.

After several years as the Hard of Hearing specialist in the Case Management Department at MCDHH, Jon now heads the Communication Access, Training and Technology Services (CATTS) Department.

Karin Williams

Karin Williams has experienced many aspects of hearing loss during her life. Born hearing, she suffered from chronic ear infections as a toddler. “I remember my mother was always putting drops of medicine in my ears. This wasn’t so bad since she always warmed the medicine up in a tablespoon lit by a match before pouring it into my ear. That always felt so nice and warm and soothing.” Her family noticed that she always crawled right next to the speaker of their old console television when it was on, even though repeatedly brought back to a slight distance, but they attached no significance to it.

“As I got older, the tomboy in me flourished and my mom frequently found me outside playing in the elements: the rain without a raincoat, the wind without a windbreaker, the snow without cap or gloves or boots,” she reports. She was plagued by constant colds and, once again, ear infections became a major part of her life. “I was not a happy camper!” she reports.

During this time, her pediatrician recommended perforating her eardrums to drain them, a popular practice in the 60’s for treating chronic fluid build-up in a child’s ear. This perforation caused scar build-up on eardrum, leading to a mild conductive hearing loss.

A first grade hearing test performed by the school nurse found that Karin had a mild hearing loss in both ears, and her parents consulted a pediatric audiologist, the first of many different audiologists,

ENTs (Ear, Nose and Throat doctors) and speech pathologists she would encounter.

Her hearing remained fairly stable until she was 12 years old, when she began to struggle in school. “I wasn’t able to understand my teachers when they talked to the class. They, in turn, were worried by my lack of attention and poor progress in my studies.” Her audiologist diagnosed a mild bilateral sensorineural hearing loss and she received her first hearing aid. “I remember when I first put it on. The sounds I heard were awesome! It was a warm spring day so the birds were singing and the trees were rustling. It was a very positive experience for me.”

Karin still struggled with the daily activities of life. Her teachers made sure she sat in the front of the class and always checked that she was paying attention. “This was great for my education, but terrible for my social situation. I hated this special treatment because my classmates didn’t always understand and I was often ridiculed and called ‘teacher’s pet.’”

Somehow, she managed with a single hearing aid but her hearing became progressively worse. As a senior in high school she received a second hearing aid. “Again, the experience was awesome. I didn’t realize how much information I was missing until I got my second hearing aid.” In an extremely mature move, she also took matters into her own hands. “Getting a second hearing aid also got me thinking that my hearing was gradually getting worse and that I would eventually become profoundly deaf. I decided to take an adult education level sign language class. I loved it and decided that I would continue to learn sign language in college and learn more about hearing loss.”

By the time she entered college, Karin’s hearing loss had become profound. “I had very little usable residual hearing, so I was basically functioning as a deaf person”. Nevertheless, she persevered through 8 years of college and graduate work, using her hearing aids, and other assistive listening devices such as personal FM systems, and auditory loop with T switch, in addition to note-takers and sign language interpreters to assist with class participation. She graduated with a Master’s degree in deafness and human services and over the next 20 years worked in several different jobs in several different states. Karin has been a case manager at MCDHH for the past 17 years.

Through her jobs, she was able to keep current with issues in technology and deafness. She was aware of the bitter controversy over cochlear implantation and, for the most part, was opposed to it. "Then about a year ago, I was visiting a dear and highly respected deaf friend of mine and she had gotten an implant. I was totally flabbergasted. As it turned out, her implant had been a great success. She can talk on any phone she wants and can go to meetings without interpreters and interacts really well with hearing family members. She feels so much more connected to the world in a much broader way than ever before."

Wanting to share the same experience, Karin went to UMass Memorial Medical Center for an evaluation. Tests showed that she was a prime candidate for a cochlear implant, her insurance company was willing to pay for the surgery and device, so she decided "to go for it."

"Getting an implant has technically made me more deaf than I was before implantation. However, a few months after my activation, I am experiencing life in a way that is totally beyond my expectations. I can talk on the phone much easier than I've ever done before. I can converse one on one without needing to use sign language. I can go to the movies without needing the FM system. It's been amazing, and I expect to continue to improve. I don't want to lose my lip-reading or signing skills, so I still use them with my deaf friends and colleagues, but I admit my life is so much fuller and easier than it has been in many years.

"So over my lifetime, I've experienced the spectrum of hearing loss from hearing as a young child to being profoundly deaf as a young adult, to experiencing hearing again through the cochlear implant in midlife. It's been an exciting ride and I for one am looking forward to continuing this hearing adventure in exploring new and vibrant technology that will enhance my ability to hear even more."

Annette Posell

Moka, a brown and black German shepherd, is lying under the table, happily extracting the marrow from a bone. A few feet away, Moka's owner is alternately speaking to one member of the State Advisory Council to the Massachusetts Commission for the Deaf and Hard of Hearing, speechreading the replies, and signing to two other people.

Annette Posell is that rare combination: a late-deafened person who is totally at ease in both the hearing world and the Deaf community. Here is her story.

One night when she was 16 and a junior in high school, she was awakened by a “blasting headache” accompanied by ringing in one ear, vertigo, and nausea. “I literally crawled into bed,” she recalls. For the next six months, the symptoms came and went, leaving less hearing each time. She spent long periods of time in the hospital but the neurologists were baffled. Within six months, she was totally deaf, but she felt grateful to be alive.

She knew nothing about deafness. There were no TTYs, no flashing signals. She hated not being able to use the phone like other teenagers, and was terrified to return to her large public high school; her father insisted that she needed the social life of school. It was during the Elvis years and she missed the music, but her friends kept her abreast of song lyrics and new singers, took notes for her in class, and studied with her.

Her parents and guidance counselor ruled out Gallaudet University in Washington, D.C. (the only university in the country for deaf students, most of whom use ASL) fearing that she would “lose speech,” and the other colleges where she applied rejected her because of her deafness. She found a home at the College of Wooster in Wooster, Ohio, “a small liberal arts college with a big heart,” and graduated with her class, having formed many lasting friendships and motivated her freshman roommate to pursue a career in speech pathology. The only job she could find was in the deaf unit of a state school for mentally retarded women. Here, she quickly picked up the basics of sign language and decided to become a teacher of deaf children. Accepted at both Gallaudet and Teachers College at Columbia University, she chose the latter to be near her husband, who was getting a doctorate from Rutgers. “Again, same as Wooster,” she recalls. “No interpreters and no legislation guaranteeing any rights. I lipread my way through school and relied on notes from friendly classmates. One coping strategy I found was to read everything in the teacher’s bibliography...and get notes from two or three classmates and combine them... . Lots of work... .” After receiving her Master’s in Special Education, she taught in a variety of settings for 12 years.

She joined The Caption Center at WGBH to help with an educational project, and was sent out on the road as the deaf spokesperson, which led to her present job of Manager of Corporate Development. “It is a rewarding job, never, ever boring, and The Caption Center and WGBH have been wonderful to me. I work in a hearing environ-

ment, providing a service originally intended for deaf and hard-of-hearing people. I always have interpreters available...and the people I work with have unconditionally and generously provided whatever assistive devices I need to accomplish my work successfully."

Annette has been active in the education of her two hearing children. "Much of my current life is spent in the hearing world and my primary communication mode is still speaking, but I feel comfortable in the deaf community and appreciate having friends who can hear and those who don't... I am grateful that I can sign, speak, and lipread and bounce between both worlds."

■ Why Do I Feel the Way I Do? The Psychological Impact of Deafness

Each of us reacts differently to deafness. Our reactions depend on many factors, among them:

- **the nature of the hearing loss: was it sudden or progressive?**
- **our individual personalities in general, and the way we respond to adversity and challenges, in particular**
- **our maturity, independence, and flexibility**
- **the support we receive from friends, family, employers, co-workers, healthcare professionals, and other people who are deaf (if we are fortunate enough to know them)**
- **what else is happening in our lives at the time**
- **what is important to us**

Nevertheless, there seem to be patterns in the way people behave, and it's useful to know what they are so we can better understand some of the emotions we may be experiencing.

In an interesting experiment, audiologist Richard Carmen once asked his hearing students to wear earplugs for one day, morning to night, and report their emotions (Hearing Loss & Hearing Aids, ed. Carmen, 1998). Every student reported feeling incompetent and inadequate. "There was a sense of limitation in areas they'd taken for granted. Simple tasks like using the telephone couldn't be performed without special focus, difficulty or strain," he wrote. "By the end of the day most of the students confessed they were unnerved and depressed."

Hearing Loss as Trauma

Acquired deafness is a traumatic loss, particularly for people who lose their hearing suddenly. It turns the way we relate to other people and to the world completely upside down. This is unique to late deafness; people who are born deaf never feel this overwhelming sense of loss because they've never experienced what we've lost.

Let's look more closely at this. At a recent workshop, Dr. Michael Harvey spoke about the basic needs of all human beings and how deafness affects most of these needs. Dr. Harvey is a psychologist who has done a great deal of work with late-deafened, hard of hear-

ing and Deaf people. More information is available in **Psychological Effects of Acquired Deafness: A Training Guide** by Harvey and Howe (1996).

- We need to feel that the universe is “just, meaningful, and controllable,” to quote Dr. Harvey. To give a trivial example: we can predict that when we drop a coin, it falls. The day that coin rises, or hangs in the air, or behaves randomly, we've lost some of the stability of our lives. Somehow, the rules have changed. That's exactly what happens when we become deaf. Through no fault of our own, our lives and bodies have become unpredictable. What's more, we can do little about it. Remember what Helen Fleming said? “I still thought.. there is nothing in this world that I can't do if I make up my mind about it.” A number of years ago, Avis mounted an ad campaign around the slogan “We try harder.” It may work for rental car companies, but trying harder won't make us hear. “One of the hardest things to accept,” says Jane Sokol Shulman of MCDHH, “is that working harder will NOT solve the problem.” As Annette Posell discovered, you may be able to tackle the situation from another angle by working harder, but the underlying problem persists and at the end of the day, you hear no better than you did at the beginning.
- We need to feel independent, able to function competently in the world and have some measure of control over our own lives. Closely related to this is our need to feel safe. Deafness also attacks this. We can no longer hear the footsteps behind us, the engine noises that warn us of an approaching car, the whistling kettle, or any of a thousand little things we've come to expect.

- We need to feel connected to the world. Dr. Donald Ramsdell in **Hearing and Deafness** (by Davis and Silverman, 1978) has noted, "Sound serves...as the auditory background of all daily living." We have grown accustomed to a background of noise in our lives—birds chirping, wind blowing, sounds of traffic, for example—so accustomed that we are barely aware of it and may even find it bothersome when we stop to listen. "These incidental noises maintain our feeling of being part of the living world and contribute to our own sense of being alive."
- We need to feel that we belong to some larger group. Deafness distances us from the hearing world to which we have always belonged.
- We also need to feel that our lives have value, the "self esteem" that everyone talks about these days. Most of us have a long road before us to regain this sense and some of us never do. There is a constant feeling that maybe we're not trying hard enough or maybe we aren't smart enough to understand people, or that our deafness is in some way a flaw in our own characters. After we've listened to people say, "It wasn't important, anyway" a thousand times, we begin to feel that maybe we ourselves aren't important. And this can be a terrible blow.

We could go on and on about this, but the point is clear that for adults who become deaf, the sense of loss can be devastating. It is fully understandable that they go through a grieving process that may last many months, even years. The effect is probably greatest for those people who suffer a sudden hearing loss, but it also strikes people with progressive hearing loss. A day arrives when they realize that they can't hear the doorbell ring, the sound of running water, or a flushing toilet, or any of a hundred things. At that moment, the sense of loss is overwhelming. "I've always known I would probably be deaf one day. The signs were all too clear: the life-long progressive loss, and the right ear, dead now for two years, was surely a clue. I was in no way, however, prepared for the shock and trauma of the reality of near-total deafness," writes Paula Bartone-Bonillas in an article in **Hearing Health**.

Let's look at some of the reactions people often have to their late deafness. These stages don't occur in neat sequence; climbing out

of one doesn't necessarily mean that we leave it behind forever. Depending on what is happening in our lives, we sometimes go back and forth from one stage to another. We shouldn't think of these stages as "bad," something to be avoided. Deafness is traumatic, and we need time to adjust to it. Grief is a very natural reaction and, for most people, crucial to the healing process. Before we can come to terms with our deafness and get on with our lives, we must grieve for what we have lost. In many ways, life will never be quite the same, but different doesn't necessarily mean worse.

Isolation and Loneliness

Newly-deafened people almost universally report a feeling of isolation and loneliness. Blake Putney, on the email discussion group Beyond Hearing (see Chapter 2), described it as living in a bubble, "When in a crowd, as at the mall, I feel like I am inside a plastic bubble which separates me from the rest of the world. This feeling of isolation prevents me from appreciating my surroundings." Others sometimes talk of a "glass wall" that separates them from the rest of society. The isolation exists on two levels. On the sensory level, we may miss the sounds of life that formed a background for living, or we may find ourselves surrounded by a babble of unintelligible voices. On the social level, we are caught betwixt and between worlds: "Audiologically deaf, but culturally hearing" is the way one author put it. We no longer feel like full-fledged members of the hearing world, but we don't belong to Deaf culture, either. There's a feeling of exclusion.

How do we deal with this feeling of detachment? The best way is probably to meet or correspond with other people who have become deafened. By learning that we are not alone, we validate our own emotions and become able to make new friendships, learn how others have dealt with their deafness, and find a place for ourselves in society. We'll introduce you to several important support groups in the next chapter.

Generally speaking, when people are deafened, they go through the stages of grief described by Dr. Elisabeth Kübler-Ross in her book, **On Death and Dying** (Macmillan Publishing Co, 1969):

- Denial
- Projection

- Anger
- Bargaining
- Depression
- Acceptance

We grieve for the loss of a very important sense. The stages do not necessarily proceed in an orderly fashion, nor do they always come in sequence. Some people skip over some of the stages, others combine some. Some people return to a stage, others get stuck in the cycle.

Denial and Projection

There is a stigma attached to hearing loss in our youth-oriented society, a belief that only the elderly lose their hearing. It's non-sense, but for those of us who are getting on in years, we may feel that to admit being deaf means that we are getting old. Particularly for people who experience a gradual loss of hearing, denial is a common response. As you've seen from my own story, I simply refused to acknowledge my hearing loss until it was severe to profound. In my case, this wasn't terribly damaging. I still went to concerts, talked on the phone, albeit with great difficulty, performed well in school, and had a wide circle of friends. But it certainly would have made my later adjustment easier if I'd faced the truth earlier. For many people with progressive losses, denial is a very real problem and uses a great deal of energy that could be better directed toward improving communication skills. Unfortunately, many people wait years before doing anything about their hearing; the average time between diagnosis and getting aids is seven years.

Another way that denial frequently manifests itself is in our difficulty saying the simple words "I'm deaf." Among late-deafened and hard of hearing people, it's sometimes laughingly called "the d-word." It seems like a very minor point, but for most of us, those words somehow seem to symbolize the entire situation, which we may be fighting against with all our energies. For many people, moving from "hard of hearing" to "deaf" is a major step.

Nevertheless, denial can have a very real emotional benefit. It allows us to lessen the impact of deafness, to handle it in small doses instead of as a single blow. But when denial continues too long, it becomes harmful. It slows down our progress towards the next

stage and delays our meeting other late-deafened people and learning new communication strategies. And in many instances, it leads us to bluff our way through conversations, which, at best, means that we get nothing from them, or try to control discussions by talking all the time - a quick way of ending up isolated! - and, at its worst, leads to embarrassing situations or costly errors that further lower our self-esteem.

What psychologists call projection is a frequent accompaniment to denial. Late-deafened people often say the reason they can't follow the conversation isn't because they can't hear. They say it's because people don't enunciate clearly these days, or because they really didn't want to listen to that silly lady's nonsense, for example. There may, of course, be some truth to these assertions, but the real reason they didn't hear is because they're deaf.

How do you help someone who is in denial? It's very difficult. In the first place, make sure that you yourself have come to terms with the loss. Don't make excuses for the deafened person: "The acoustics in that hall were awful!" "That actor mumbled his lines." Don't coddle or overprotect the deafened person out of a false sense of compassion. Be honest. For example, staying home with your late-deafened spouse rather than joining friends for dinner, under the pretense that you aren't interested, will only foster a sense of sacrifice and resentment on your part. Much better to join your spouse for dinner and create a positive environment by explaining - and at least initially, enforcing - good communication practices.

For some people, a kind of shock treatment can be very helpful. In graduate school, I met and became friends with someone who was hard of hearing. She saw immediately what I was doing. When she called on the telephone and sensed that I wasn't following the conversation, she would bark, "What did I just say?" I was ready to kill her, but it made me realize how little I was actually hearing of our conversations.

But perhaps the best way to help is to be patient, knowledgeable, and understanding. Try to minimize your own frustration. Taking the initiative to learn about support groups and other resources (Chapter 2), assistive technology (Chapter 6), auxiliary services (Chapter 7), and communication skills (Chapter 4) can be very helpful. Offer to help with speechreading or enroll together in a sign language class (see Chapter 3). Offer the information, but only if the

person seems receptive. Try to be calm and patient, admittedly difficult when dealing with such an emotional issue with a late-deafened person who may be very angry and confused.

Anger

It's only natural to feel angry when terrible losses befall us through no fault of our own. The anger is sometimes directed at the universe, or toward God, the medical profession, one's family, or even oneself. It's easy to become caught in a bad case of what Helen Fleming calls the "Why me's?" The sooner we realize that often no one is to blame for uncontrollable things that happen, the sooner we can re-direct our energies in more positive ways. "It is okay to be angry at times," writes mental health therapist Maureen Mann, who herself has a severe hearing loss, "but it is not okay to hold on to that anger until it destroys your self-image, controls your life, affects your relationships with your loved ones, and damages or inhibits your career."

Bargaining

When we encounter loss, we often try to bargain with what we perceive to be the cause of the problem. "Let me live long enough to see my grandchild," we may say. Or "Ears, just give me back hearing in one ear and I'll never attend another hard rock concert."

Depression

We would be less than human if we didn't become depressed when we first become deaf. We have, after all, suffered a great, incomprehensible loss and may feel like helpless victims. Depression can be overwhelming, almost paralyzing. During this stage, we need compassion and support from friends, family, and the medical profession. We need, above all, to try to talk about how we feel. As we put our feelings into words, they become more manageable. "The very act of telling the story to another human being who cares, who listens, who attempts to understand, is part of healing," says psychologist Michael Harvey. We begin to see that with creativity and hard work, and "a little help from our friends," we may be able to make changes that will help us in difficult situations. However, if your depression is prolonged or interferes with your life, or if you seem mired in a "victim mentality," you should find a professional with experience in treating people who are deaf. Contact the Massachusetts Commission for the Deaf and Hard of Hearing. Speak with your doctor. Depression is treatable.

Acceptance

The goal of adjusting to deafness is to acknowledge it so we can get on with living our lives. This involves renouncing the role of victim, moving past the things we can't control and taking control of things we can control or change in our lives, moving from withdrawal to active participation. It's the point when we realize that we remain basically the same person as before, that we ourselves are in no way damaged, only our ears are. This allows us to adjust old relationships, form new ones, and personally grow from the experience of having to surmount great personal loss and suffering.

Acceptance doesn't mean that we will never again miss sound. A miscommunication with an insensitive co-worker, the birth of a child we will never hear, a concert by a favorite musician, and similar events can all trigger emotions that we thought we'd laid to rest. The pain may never completely fade, but in time, we become desensitized to such situations and they become easier to handle or even laugh at. Helen Sloss Luey and Myra S. Per-Lee, in **What Should I Do Now? Problems and Adaptations of the Deafened Adult** (Gallaudet 1983), have even suggested that "it is not realistic to expect total acceptance, and it is likely that discussion of acceptance in the literature and by professionals has contributed greatly to people's feeling of inadequacy."

■ The Effect of Deafness on "Real Life": At Home, Work, and Play

It's difficult for hearing people to understand just how fully deafness pervades our lives. How do you manage using a telephone? Group discussions? Intimate moments in candle-lit restaurants or even in bed in a darkened room with your loved one? We'll discuss some of these in detail in Chapters 8 and 9, where we discuss coping strategies. This section describes some of the ways deafness can affect everyday relationships.

Family and Friends: Relationships and Hearing Loss

"It is surprising," writes Jonathan O'Dell, "that most often, the biggest handicap cited by deafened people is their family. Behaviors are hard to change, and someone who does not understand how changing environments can influence comprehension may be quick to assume 'You only hear when you WANT to hear!'".

After you lose your hearing, you and your family and friends will have to re-write the “rules” that guide the way you interact. Much of this will be through trial and error. Similarly, if your hearing improves significantly after you receive a cochlear implant or hearing aids, you may again have to adjust family relationships. We'll discuss this latter situation in Chapter 5.

Family and friends often go through a process of grief, too. I have stacks of clippings describing all kinds of new research into “cures” for hearing loss, from acupuncture to vitamins to cochlear implants. They were sent to me by well-meaning people who were searching for a magical cure for my ears. Your deafness may be very hard for family and friends to accept. In addition to their distress at watching helplessly as you suffer through the first stages of shock and grief, it also makes them think about other painful topics: growing older, death, changes in family roles, etc. It's important to realize that they, too, are suffering and in pain. Usually, however, they're reluctant to focus attention on themselves and admit their condition, since they feel it may add to your distress and somehow feel that it is less “valid” than yours. Anyone who has watched a family member or friend who is chronically or seriously ill or disabled knows how the focus in a family shifts to the victim, while the emotional needs and well-being of other family members may be pushed aside. (For a fuller discussion of this, see David Luterman's **In the Shadows: Living and Coping with a Loved One's Chronic Illness**, 1995. Michael Harvey also illustrates this in a case study of “Vicarious Hearing Loss: A Spouse's Tale” in **Listen with the Heart: Relationships and Hearing Loss**, 2001.)

Hearing loss may make subtle changes in the way the family “works.” The kids may no longer be able to yell for Mom when they need a glass of water in the middle of the night. Dad may no longer be able to mediate family arguments. Your book discussion leader may no longer be able to follow group discussions. Jobs may change; careers may take detours. “Your experience has been so intense that you cannot possibly emerge from it unchanged,” write Luey and Per-Lee. “...Perhaps you have found more internal strength than you knew existed. Your priorities may have changed, and you may view the world and other people with new sensitivity, seriousness, and compassion. Some people may not understand or accept the new person you have become.” Late-deafened adults almost universally speak of finding out who their “**real** friends” are

when they become deaf. Losing old friends isn't fun, but you can compensate by making new ones, strengthening old friendships, and exploring new areas of interest.

Jettisoning insensitive family members isn't so easy, of course, although all of us, hearing and deaf, no doubt have at times been tempted. Making family and marriage "work" is a job for everyone involved. You will have to be open and honest with each other. Even if you're the shy, retiring type, you must take the initiative and explain how others can best communicate with you; the suggestions, which we'll discuss in Chapter 4, are fairly simple, but changing ingrained communication patterns is always difficult. The best policy is probably for everyone to be honest about their concerns and frustrations. You may need to explain that speechreading is very tiring, that there are some events you'd rather not go to because you already know there is simply no way you will be able to function well in those environments. Or you may have to set down rules for telephone conversations with other family members. There is nothing quite as maddening as watching a spouse have a 15-minute conversation with a son away at school, only to have the conversation summarized for you in a single sentence. The only way to set rules with which you can live is to think through your needs fully, then negotiate with family and friends, keeping in mind that their needs, even when they conflict with yours, are just as valid.

In many families, certain members fall into the role of "interpreters." They answer telephone calls, help with conversations at social functions. This can lead individuals to become dependent, or, alternately, to be resentful that their independence is being usurped. And the "interpreter" can feel burdened and angry. It's best to discuss these matters together and find out what is best for everyone. A successful solution is one that meets your special needs but is also considerate of other members of the family. Each of you will have to try to walk a mile in the other's shoes.

Although it's always useful to find out how other deafened people handle the problems we face, what works for them may not be quite right for you. Many late-deafened people, for example, become furious if a family member doesn't let them conduct their own telephone conversations, but rather "helps" them out. For me, that isn't a problem. At my summer business in Vermont, when the phone rings, I often ask anyone who is around to take the call and "translate" for me. I don't feel that I'm surrendering my independence. I

don't need practice making business calls or explaining how callers can tell me their phone numbers so I can call back using the Telephone Relay Service (see Chapter 7). For me, it's a question of efficiency. My own telephone calls using a TTY are very tedious and time-consuming. If a working pair of ears happens to be in the house, I just make use of it. But other late-deafened people feel very differently.

"The resolution of communication problems and the resulting rifts in relationships, does not require major alterations in the ways in which families do things," writes Dr. Sam Trychin, whose workshops on coping strategies for hard of hearing people have become almost legendary. "Rather, it is more frequently a matter of changing a little something here and a little more there. A number of minor adjustments in behavior can easily add up to major changes in attitudes, expectations, and emotions."

In **An Invisible Condition: The Human Side of Hearing Loss**, Rocky Stone, founder of Self Help for Hard of Hearing People (now HLAA; see the next chapter for more information) talks about meals with his family. "At the dinner table, family members take turns, in a very natural way keeping me posted: 'Rocky, we were talking about...' 'Dad, we are discussing...' And so it goes throughout the meal... The effort being made on my behalf goes far beyond the courtesy of keeping me involved. It is an act of love."

At Work

You will need all your creativity, energy, and people skills to optimize your work situation. We'll discuss ways of dealing with specific problems in the remaining chapters. You may find that you can, to some extent, control your listening environment. You can train co-workers in communication strategies (see Chapter 4). You can make use of assistive technology (see Chapter 6) and auxiliary services (Chapter 7). You may have to change your role and responsibilities, or even change your career goals. This is another area where the support groups we'll discuss in the next chapter can be invaluable.

In her book, **Coping with Hearing Loss** (Barricade Books), Dr. Susan Rezen, Professor of Audiology at Worcester (Mass.) State College, suggests that you hold a training session for your co-workers to explain your hearing loss, suggest communication strategies, and discuss how to maximize your benefits from speechreading and hearing aids, if you wear them. Some companies can be very

responsive. We saw how WGBH has provided Annette Posell with interpreters and assistive devices. In Chapter 9, we'll discuss what accommodations companies are required by law to provide for you. When product engineer Howard Samuels lost his hearing several years ago, the **Boston Globe** reported how the company for which he worked, Analog Devices in Wilmington, offered his co-workers American Sign Language (ASL) classes on company time, captioned the videotaped annual reports, and provided him with a number of assistive devices. Samuels had been with the company for 11 years and was fluent in Japanese and French. He was grateful to the company and his co-workers, but quick to point out that Analog Devices' efforts were a good business investment, because they enabled the company to retain an experienced employee in a useful and productive role; "It costs a lot of money to bring one skilled employee like myself to the company," he explained.

You might also suggest that your company contact the Massachusetts Commission for the Deaf and Hard of Hearing for a training session by the Communication Access Training and Technology Services (CATTS) Department. The department can also offer technical advice, and make informal recommendations as to how to improve overall communication policies and sometimes even on how to improve the actual physical environment.

Nevertheless, sometimes it just isn't possible to continue in your present job or even at your present company in another capacity. Losing one's job is a wrenching experience. For starters, you may want to sit down and analyze your strengths and weaknesses. You can consult case managers at MCDHH, speak with Independent Living Specialists for the Deaf and Hard of Hearing or Rehabilitation Counselors for the Deaf. Chapter 2 discusses some of the support services that are available to you.

Many late-deafened adults, after learning sign language, have discovered that this new skill presents new job opportunities and opens alternative career doors. Many, having experienced the trauma of deafness or even come near death, find that their focus and goals have changed; different things have become important. A common thread runs through discussions with many late-deafened and severely hard of hearing people: "My own experience was so difficult, I want to do something to insure that other people don't have to go through the same suffering," they say. Helen Fleming has spent her retirement advocating for hard of hearing people. Karin Williams

and Jonathan O'Dell chose to work at MCDHH, where they can help people going through similar experiences. Annette Posell works at the WGBH National Center for Accessible Media, which provides a valuable service for people with hearing loss. I've written this book.

Recreation and Social Life

Does deafness spell the end of social life? Certainly not, as long as you bring a certain flexibility and creativity to the situation. After all, one of the favorite activities at gatherings of the Association of Late-Deafened Adults (ALDA) is karaoke! In Chapter 6, we discuss assistive devices you may be able to use; Chapter 9 describes coping strategies that can be of some help. You can probably do everything you did before you lost your hearing. You may just have to do things differently or not as well, but that doesn't mean you can't enjoy yourself. As we'll see, there are captioned movies, quiet corners of restaurants, and smaller, more intimate dinners. Town meetings and church activities become accessible with assistive listening devices and interpreters. Many deaf people are excellent dancers, able to feel vibration through the floor or pick up the low frequency beat. A knowledge of American Sign Language opens doors to activities within the Deaf community and new friendships. Support groups like ALDA and the Hearing Loss Association of America (HLAA) host frequent gatherings and like any other meetings, usually begin with some socializing. The annual conferences of these groups are opportunities to meet old friends, make new ones, and see new sights.

■ Special Concerns of Senior Citizens

The incidence of hearing loss increases dramatically with age. One third of all people over the age of 60 and 50% of people over 80 have some form of hearing loss. As a 1986 report by the Office of Technology Assessment concluded, "Hearing impairment is very common among elderly people and can seriously affect their safety, quality of life, and ability to live independently." Many of the difficulties of late deafness are magnified for the elderly population:

- Some seniors may not be as comfortable with new technology as younger people. They may shy away from using assistive listening devices and closed captioning on television sets because they may seem to be complex. Seniors may lack the manual dexterity to manipulate the controls on hearing aids and assistive listening devices, and may be unaware of adaptations that eliminate such difficulties.

- It's hard enough to adjust to deafness in the familiar, comfortable surroundings of one's home. Many seniors who have moved into nursing homes or live with relatives find themselves in an unfamiliar and somewhat hostile environment that makes adjustment even more difficult. The Massachusetts Commission for the Deaf and Hard of Hearing often holds training sessions for staff of nursing homes to sensitize them to the problems, characteristics, and needs of individuals who are severely hard of hearing or deaf, and to teach ways to improve communication.
- Seniors may feel very anxious about maintaining their independence and their ability to live in their own homes, yet may be unaware of or avoid using safety alerting devices and other assistive technology (Chapter 6). As a result, deafness and its associated "incidents" (bathtubs that overflow, kettles that boil dry, doorbells unanswered, etc.) may threaten their independence, leading to further anxiety and depression.
- It's dangerous to generalize, but as a group, seniors tend not to be as assertive as younger people and seem to shy away from calling attention to themselves. Hearing aids and assistive devices might make them seem "different." Connecting with peers at HLAA and ALDA groups can be very helpful.
- They may experience great disappointment in not being able to hear their grandchildren's voices and participate fully in family gatherings. Inappropriate answers, due to not fully understanding the conversation, may be taken as evidence that "Grandma's mind is beginning to wander."
- Deteriorating vision, another common accompaniment of aging, can make speechreading difficult. If reading is already a chore, then the individual may spend more time watching television or listening to the radio. Deafness may make this impossible without assistive technology, further disrupting life.
- Caregivers, family, and healthcare providers are not familiar enough with assistive devices that can be of great use to seniors.

Nan Robbins, former Deputy Commissioner of the Massachusetts Commission for the Deaf and Hard of Hearing, recalls her paternal grandfather, who was deafened as the result of an accident while working on the railroad. "Looking back, as a young child I was rather mystified by him, not really understanding that he could not hear well at all or just what that meant in practical terms. . . . I was not exactly afraid of him, just remote from him... . My child-speech was probably very difficult for him to understand, I now realize. And looking back, the family was not very clever in "getting it" about his hearing loss, and how to communicate more easily. The strategy, I suspect, tended to be avoidance rather than accommodation.

Today, hearing aids are vastly improved, and there is much more information available to families to assist communication with the deaf family member."

■ Special Concerns of Teenagers and Young Adults

Like seniors, teenagers don't want to be different from "the crowd." Unlike seniors, they also feel a sense of their own invulnerability.

When Helen Fleming learned that she had a progressive hearing loss, her reaction was in many ways typical. "Being 19 years old, my attitude was, so what? What the heck's wrong with not being able to hear okay? I'm very lucky. I have two feet, I have two arms, I have a good head. I have excellent vision. What am I worried about? So I can't hear a little bit."

For teens who become totally deaf, the situation is different, but many of the concerns are the same. Annette Posell, whom we also met at the beginning of the chapter, became deaf over a period of six months at the age of 16. She says that losing her hearing changed her life, but it wasn't a particularly sad experience. "I had youth on my side," she says. "And I was very sick and thought that I would die, so becoming deaf was not so much compared to that." In school, the fact that she couldn't hear was "the only difference between me and the other students."

She remembers how relieved she was when the audiologist told her that hearing aids would be useless. "I did not want to use a hearing aid because at age 16, boys were just beginning to interest me. The thought of a boy putting his hands through my hair and getting wound up in wires was too much!" (Hearing aids at that time were large and cumbersome.) What she hated most was not being able to

use the telephone herself. (TTYs were not yet available.) Her parents “would have the conversation, and tell me about it after they hung up.” Her brother seemed overprotective and her father made her take a special driving test he concocted. She was terrified of returning to her large public high school, but her friends helped her out in many ways. However, nobody at the school seemed to know how to deal with her. An English teacher tried to remove her from his class. “I credit him now, although I hated him then, for creating in me a drive to prove I could do something that people said I could not. I got an A in his class only because I felt the need to prove him wrong!”

What help is available today?

Annette became deaf quite a few years ago, before many services and technological advances were in place. Today, the law, support groups of others who become deaf, assistive technology, and auxiliary services are readily available. You'll find information on these topics throughout this book.

- **Emotional support:** Talking with peers who have become deaf or adults who became deaf when they were teenagers can be very helpful, as can talking with a special counselor or therapist about adjustments and feelings. There are a number of therapists and counselors in Massachusetts who have special training and understanding about deafness. Some of them are themselves deaf or hard of hearing.
- **Access to the telephone:** Annette found her inability to use the voice telephone a major problem. Today, teenagers who become deaf have a lot of resources in this area (Chapter 6). Today we have TTYs, captioned phones, the Telephone Relay Service, fax, text messaging, Instant Messenger, and email.
- **Access to what the teachers are saying:** Most teenagers who become deaf take classes to become proficient in speechreading (Chapter 3). Especially if some residual hearing remains, it can be very useful, more so when used with other communication strategies (Chapter 4).

Some late-deafened students use Oral Transliterators (Chapter 7), so that a very clear “picture” of what the teacher and other students are saying is available. In addition, many teenagers decide to learn American Sign Language (Chapter 3) so that

they can use ASL Interpreters in classes, and also so they can meet Deaf individuals who can give tips on life as a Deaf person. Today, several high schools offer classes in ASL, some for foreign language credit. Schools are usually quite willing to educate students and staff about hearing loss, communication between deaf and hearing people, and American Sign Language.

During the past several years, Communication Access Realtime Translation (CART Service; see Chapter 7), in which the spoken proceedings are projected on a screen, has become available and is used by many late-deafened students in high schools and colleges to provide access to lectures and group discussions.

- **Practical information about relationships and social activities:** Information about socializing with hearing partners, how to deal with parties, etc. is best gleaned through talking with others who know. Make connections through ALDA (Association for Late Deafened Adults), MCDHH, HLAA (Hearing Loss Association of America), and the DHILS programs and services (Deaf and Hard of Hearing Independent Living Services/Programs). See Chapter 2.
- **How laws help:** State and federal laws require schools to provide certain special services (listening systems, interpreters, CART service, note-takers, counseling, tutoring, and so on). In elementary through secondary schools, such services can be obtained by stipulating them in the Individual Education Plan (IEP) that students with special needs (including hearing loss) can file. Special services at the college level are also required in most circumstances. Information is available from the Massachusetts Rehabilitation Commission, Rehabilitation Counselors for the Deaf; and also from MCDHH and the DHILS services (Chapter 2), and to varying degree, from your local school department.

Use the Massachusetts Commission for the Deaf and Hard of Hearing as a central point of contact and information. Their website, www.mass.gov/mcdhh, contains much valuable information.

2. WHERE TO TURN FOR HELP

When the sounds you have heard all your life suddenly stop, it's natural to feel isolated and excluded. But you are not alone. Late deafness is fairly common and there are many shoulders to lean on. In this chapter, we discuss support groups and services that can help you adjust.

Support Groups

Most late deafened people coping with a hearing loss find it helpful and reassuring to meet others who are in the same boat and have experienced the same emotions and difficulties. There are several national organizations, with chapters in each state, each with a different focus. If you speak to members of these groups, many will tell you the same thing: that the support group has become a second family, a refuge where they are fully accepted and their communication needs are understood. As Jane Sokol Shulman, who would later become president of the Boston chapter of the Association for Late-Deafened Adults (ALDA), has noted: "In the course of buying my first TTY in the summer of 1991, I saw a newsletter from ALDA-Boston...and made contact with them...To me, it meant my first encounter with another person who had experienced adult-onset hearing loss...Twenty years after my first medically documented significant hearing loss, finally for the first time I met another human being who had gone through what I went through."

We list some of the leading organizations here. You can find contact information in the Appendix.

Acoustic Neuroma Association (ANA)

"ANA is a patient member organization, providing information and support to persons diagnosed with or treated for acoustic neuromas and other benign tumors of the cranial nerves."

Alexander Graham Bell Association for the Deaf and Hard of Hearing

"The Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) is a lifelong resource, support network, and advocate for listening, learning, talking and living independently with hearing loss. Through publications, outreach, training, scholarships and financial aid, AG Bell promotes the use of spoken language and hearing technology." The Association is made

up of three sections: Parent Section, International Professional Section and the Deaf and Hard of Hearing Section. Bell Kids was established in Massachusetts in 2003 as a mentee and support program for kids ages 8 to 12. The program is sponsored and overseen by the Alexander Graham Bell Association for the Deaf and Hard of Hearing.

Association of Late-Deafened Adults (ALDA)

"Since its founding . . .," writes ALDA-Boston past president, Carol Menton, "ALDA has been a state of mind as well as a thriving international group for folks with acquired deafness. Its communication philosophy of 'whatever works' is what ALDA is all about. The organization promotes peer connection, support, and mutual respect for the various choices that members make about communication and life with hearing loss. Through its newsletters, annual convention, national and local advocacy, and local chapters, ALDA provides a network of connections and support for those who've become deaf after having acquired spoken language. New members are warmly welcomed!" Both the national and Boston organizations publish quarterly newsletters, **ALDA News** and **ALDA-Bostonian**, respectively. ALDA hosts its annual convention, known as ALDAcon, in various cities around the country.

Kathryn Woodcock, the first deaf president of the Canadian Hearing Society and a former ALDA board member, has written about ALDA's official communication policy: "whatever works." "If that entails standing on your head and blinking in Morse code, then we try to work with that. Pencil and paper, keyboards, cochlear implants, fluent sign language, lousy fingerspelling, lipreading, and a great deal of laughing are all observable at ALDA gatherings."

Hearing Loss Association of America (HLAA)

(formerly Self Help for Hard of Hearing People, Inc. (SHHH))

"The Hearing Loss Association of America is the nation's largest organization for people with hearing loss. The Hearing Loss Association of America exists to open the world of communication for people with hearing loss through information, education, advocacy and support."

Founded in 1979 by the late Howard "Rocky" Stone, HLAA has grown to be the largest of the national support groups for people with hearing loss, with over 250 local chapters across the country. Members span the continuum of hearing loss. The national organi-

zation publishes a bimonthly journal, **Hearing Loss**, and holds annual conventions each summer. HLAA has published a large number of reprints, booklets, and information packets, and sells books about hearing loss from its national office. The organization has taken a leading role in advocating for people with hearing loss. There are several local chapters of HLAA in the state. They publish their own newsletters, hold monthly meetings, and provide peer support.

Massachusetts State Association of the Deaf, Inc. (MSAD)

"The Massachusetts State Association of the Deaf, Inc. (MSAD) is a statewide, non-profit organization serving more than 500,000 Deaf and hard-of-hearing individuals in Massachusetts. We have two offices in Malden and Springfield. We advocate for the rights of, and serve the needs of, Deaf and hard-of-hearing individuals statewide." MSAD produces a newsletter, the **Deaf Community News (DCN)**, and runs a Sign Language Education program.

Minuteman Implant Club (MIC)

"The Minuteman Implant Club is an organization of implant users, family, friends, and professionals that have an interest in cochlear implants." MIC meets five times a year "to share experiences, listen to guest speakers, and support one another." Children's activities are scheduled during meetings. The club publishes a newsletter, **The MIKE**, and also hosts a large biennial weekend convention in Sturbridge, MA.

The NF2 Crew

The NF2 Crew is "an informational and support group for people with NF2 [ed. note: Neurofibromatosis Type II, recurring tumors affecting the auditory nerve] and their family members," conducted through email messaging.

Organizations Offering Support Services

There are also several agencies and organizations that offer peer counseling, support, and other specialized services for late-deafened adults.

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

- MCDHH is a state agency and the central agency for informa-

tion and a variety of specialized services for Deaf, late-deafened, and hard of hearing people in Massachusetts, for their families, and for providers of services.

MCDHH is often a good place to start when you are looking for information or assistance. For example, MCDHH provides:

- general information and referral
- direct information and education for consumers about topics related to communication
- case management services (see below) for children and adults
- information on assistive technology, help in finding out what might work for you at home and at work
- interpreter and CART Referral Services
- payment for CART and Interpreter Services in situations where other agencies are not mandated to pay
- training in how to provide communication access, for private, public, and state agencies
- referral to self-help groups where you can meet other people who are late-deafened, have a hearing loss, or are Deaf
- assistance in finding appropriate services and programs

The **Department of Case Management Services** at MCDHH employs bilingual staff who are fluent in English and American Sign Language. Many are Deaf, hard of hearing, or late-deafened themselves. Here are a few of the questions that the Case Management Services Department can help you answer:

- What can I do to cope at work, at home, and in the community?
- What assistive technology can I get to help me feel safe at home?
- How can I learn to speechread better?
- How can I know how to identify a qualified hearing aid dispenser?

- I am curious about American Sign Language and signed English. Where can I visit a class or meet people, including late-deafened people, who are studying either of these?
- Where can I go to get financial aid?
- My life is just falling apart. Who can help me?
- What special services and programs are available to help me?

DHILS (Deaf and Hard of Hearing Independent Living Services/Programs)

There are ten DHILS programs in the state. They serve Deaf, late-deafened, and hard of hearing people, providing independent living services such as skills training and peer counseling, emergency intervention, self-advocacy training, assistive technology demonstrations and loans, sign language and communication classes and workshops. The DHILS programs are staffed primarily by individuals who are Deaf, late-deafened, and/or severely hard of hearing. Services specifically for late-deafened people vary somewhat from program to program.

2

WHERE TO TURN FOR HELP

Boston Guild for the Hard of Hearing at Northeastern University

"The Boston Guild for the Hard of Hearing was founded in 1916 and was originally called the Speechreader's Guild. The vision of the Guild at that time was to establish a haven where the problems associated with hearing loss would be understood and addressed.

Northeastern University was chosen to continue the Guild's mission of providing the highest quality of services to hard-of-hearing individuals and to the community. The Boston Guild for the Hard of Hearing at Northeastern is committed to serving the needs of people with hearing loss and finding innovative ways to disseminate information to professionals and others in order to increase awareness about the total impact of hearing loss and the importance of hearing conservation."

The Guild offers several programs for hard of hearing people, including Hearing Instrument Outreach Program, Assistive Listening Device Program, Aural Rehabilitation and Speech Reading Classes and the Community Outreach Program.

Hearing Rehabilitation Foundation (HRF)

"The Hearing Rehabilitation Foundation (HRF) is a non-profit organization formed in 1996 to provide and promote speech communication training for children and adults with hearing loss. The past twenty years have seen many exciting technological innovations for people with acquired profound hearing losses. These have included greatly improved hearing aid designs, specialized assistive listening devices, the introduction and rapid development of cochlear implants, and innovations in tactile aid design. Despite these developments, it is apparent that technology is not always enough, and that some people with acquired deafness require special additional assistance even after the fitting of the most appropriate devices." To this end, the HRF offers occasional workshops on lipreading, music and cochlear implants, and other topics, as well as one-on-one instruction.

Computer Forums and Support Groups

The Internet has a wealth of information about hearing loss. In addition to manufacturers' websites for every imaginable hearing device, forums for organizations that support both professionals in the field and consumers, there are also several email discussion groups (listservs). Whenever I have a question about a detail, I first post a message on several of these lists. Often, I have an answer within minutes. As with all advice on the Web, you should maintain a healthy skepticism, since the reply may have no validity whatsoever, but there are many professional and amateur experts who frequent these lists who are quite knowledgeable and very generous with their time. It is always a good idea to cross-reference any information you obtain from at least three or more sources.

Beyond Hearing

This is one of the most interesting lists for late-deafened people. Founded by the late Dr. Muriel (Mimi) Clifford on the Duke University computer system in the 1990's, the list is now on Yahoo and is owned by Emilie Quast, a cataloguer at the University of Minnesota libraries.

The list "is intended to provide a communication vehicle for people who have a hearing loss and who seek to overcome the barriers of hearing loss between themselves, other people, and the environment. Hard of hearing people, Hearing Loss Association of America (HLAA) members, Association of Late-Deafened Adults (ALDA) members and such other persons as might be interested are invited to join us."

Better Hearing News (bhNews)

An offshoot of Beyond Hearing, "Better Hearing News (BhNews)", owned by Bob MacPherson, is dedicated to the dissemination of interesting and beneficial information for the 'Hearing Loss Gang,' and more." Message volume is high and discussions can be off-topic.

SayWhatClub

The SayWhatClub "is dedicated to enhancing interpersonal communication for people who are hard of hearing, deafened, or have serious interest in hearing loss."

HearingExchange

HearingExchange is lawyer and cochlear implantee Paula Rosenthal's "supportive community for people with hearing loss, parents of deaf and hard of hearing children and professionals who work with them. It provides an open forum for the discussion of ideas and information on hearing loss and related issues."

Hearing Loss Web

"Hearing Loss Web is dedicated to people who have hearing loss, but are not members of the traditional Deaf community. This includes people who consider themselves to be hearing impaired, hard of hearing, late deafened, and oral deaf. We provide information on issues, medical topics, resources, and technology, and events related to hearing loss." The owners of the site are Char and Larry Sivertson, longtime activists in the San Diego area.

Hearing Mojo

David Copithorne lost his hearing suddenly a few years ago. His website offers "reviews of medical and over-the-counter products for people with hearing problems. There are articles on coping strategies, industry news, and links to advocacy organizations" and blogs.

■ Mental Health Counseling and Emergency Intervention

There are a number of mental health therapists in Massachusetts who specialize in working with Deaf, late-deafened, and severely hard of hearing people. Late-deafened people have often found mental health therapy very valuable, sometimes just to "talk it through, sort out feelings, and find coping strategies." Others have even found it life-saving when they were overwhelmed by the experience of losing their hearing.

Career Help

Many people who become deaf, especially when it is sudden, often have to make major changes to continue their careers, and may even have to find alternate employment. They may need special equipment, such as assistive devices, or may have to develop new communication strategies, change departments, perhaps even change their job objectives.

The Massachusetts Rehabilitation Commission (MRC) has specialized counselors for the deaf and also provides job training. (See full listing under Financial Assistance later in this chapter.) An MCDHH Case Manager can steer you to the appropriate resources, which often involves specialized technical assistance from MCDHH's Communication Access, Training and Technology Services (CATTS) Department.

Medical Help

There are several medical procedures which are available for the treatment of selected cases of late-deafness. You should consult an otologist or otolaryngologist to find out if these might be appropriate for you. For a discussion of hearing aids and cochlear implants, see Chapter 5.

Treating Drug-Related (Ototoxic) Loss and Autoimmune Reactions

Most late-deafness is the result of damage to the inner ear and is not reversible through medication or surgery. Occasionally, sudden drops in hearing due to medication may be reversed by discontinuing the medication. And some losses due to autoimmune reactions have been successfully treated with steroids. In these cases, it's important to consult a specialist as quickly as possible if you notice a sudden and inexplicable change in hearing acuity. Even then, the prospects aren't bright.

Financial Assistance

Late deafness may mean a drop in income, as we are forced to change jobs and careers. With a pair of digital programmable hearing aids costing well over \$3,000 and cochlear implants running about \$50,000, most late-deafened people wonder if there is any possibility of receiving financial support. Although the IRS doesn't give a deduction to deaf people such as it gives to the blind, there

are a number of sources of financial assistance for basic income, job-retraining, and for purchase of hearing aids and other technology. Start by contacting MCDHH about a variety of resources to assist in purchasing assistive technology .

In spite of the expense of treating hearing loss, it makes good financial sense to do so, if for no other reason. According to a recent report by the Better Hearing Institute, untreated hearing loss cuts income by an average of \$23,000 per year.

■ Benefits Programs

Social Security

Late-deafened people who qualify can receive disability benefits through SSI (Supplemental Security Income) and SSDI (Social Security Disability Income).

SSI is a means test program based on financial need. Disabled individuals who are eligible for SSI benefits are those who have never worked or who have not earned the required amount of work credits paid into the social security system. In addition to receiving a monthly check, a Massachusetts resident who is eligible for SSI is also eligible for Medicaid insurance. To qualify for SSI, you must meet certain

2 financial eligibility criteria demonstrating general financial need.

SSDI pays a monthly check to people who have worked and paid into Social Security and have developed a disability. An individual who cannot return to his or her chosen work but can perform “gainful” work, is not considered disabled. Recipients of SSDI automatically qualify for Medicare insurance after 24 months of receiving SSDI.

The application process for SSI and SSDI is complex and involves restrictions on the amount of income that can be earned in addition to the SSI or SSDI benefits.

Medicare Insurance

If you were a working individual who paid into the Social Security system, you may be eligible for Medicare. Medicare covers a wide range of medical benefits, but does not currently cover the cost of hearing aids, batteries, or anything else related to hearing aids. Hearing tests are covered but must be for “medical diagnosis” only, not for evaluations for hearing aid fitting. Cochlear implants are covered for individuals who meet certain criteria. A person eligible for SSDI is eligible for Medicare.

Medicaid Insurance (MassHealth)

If you qualify for SSI, you will also qualify for Medicaid insurance. Medicaid provides a range of hearing-related medical benefits, including purchase of hearing aids, coverage for minor repairs, and for audiological test. “Minimal” coverage is provided for cochlear implants.

CommonHealth

CommonHealth offers comprehensive health insurance coverage, either primary or to supplement other insurance policies. The policy, which is billed on a sliding scale, pays for medical and dental office visits, hospitalization, medication, medical equipment, and many services not covered by most health insurance policies. Of particular importance to late-deafened adults, CommonHealth covers audio-logical/hearing exams and evaluations, earmolds, hearing aids, batteries, accessories, and repairs, and speech/language therapy.

New eligibility requirements went into effect July, 1997. You are eligible if you are a Massachusetts adult with a “permanent” disability who is ineligible for MassHealth and either:

- unemployed or employed for less than 40 hours/month (in which case there is a one-time deductible), or
- employed for more than 40 hrs./mo. (no deductible)

Massachusetts Division of Medical Assistance (DMA)

Provides audiological and hearing aid evaluations for all people eligible for Medicaid.

Massachusetts Rehabilitation Commission

The Vocational Rehabilitation Dept. of the Massachusetts Rehabilitation Commission (MRC) provides a wide range of benefits and services to late-deafened individuals who are eligible. MRC may cover the cost of assistive technology (hearing aids, TTYs, assistive listening systems, signal devices, etc.) when these are needed for employment. They also have a ‘loan program’ to assist in obtaining technology. MRC also provides coverage for vocational training, re-training, driver training, and vehicle and home modifications for eligible individuals.

MassMATCH (Maximizing Assistive Technology in Consumers' Hands)

"The purpose of MassMATCH is to put assistive technology (AT) into the hands of people with disabilities." It consists of four programs:

- Device demonstration program
- Device short-term loan program
- Device re-utilization program
- State financing activities

The program is funded by the Rehabilitation Service Administration (RSA) of the U.S. Department of Education and lets people see, touch, and try out assistive technology.

State financing activities include:

- AT Loan program: MRC, Easter Seals MA and Sovereign Bank offer reduced rate loans so that people with disabilities can purchase AT equipment.
- Home Modification Loan Program: MRC and the Community Economic Development Assistance Corp. (CEDAC) offer reduced interest rate loans up to \$25,000 for homeowners with disabilities who need to make access modifications to their principal residence.

In addition, the AT Exchange of New England is a free AT device exchange program offering the opportunity to sell used AT equipment.

Massachusetts Equipment Distribution Program

Deaf and hard of hearing people in Massachusetts can receive free TTYs, signaling devices, and amplifiers (see Chapter 6) through the Massachusetts Equipment Distribution Program. In addition, certified TTY users can apply for a discount on their local and long distance telephone service. The program is funded by a surcharge on all voice and data telephone lines. See Chapters 6 and 7 for more information about assistive devices and services.

U.S. Department of Veterans Affairs (formerly Veterans Administration)

Many military personnel sustain hearing loss, mainly from exposure to noise. Financial assistance may be available to veterans whose hearing loss is related to in-service injury.

Title VII Part B

This is federal money made available to all of the DHILS programs and Independent Living Centers in Massachusetts for purchase of equipment and services to help people to maintain or achieve independence. The program can provide funding for assistive technology but there is generally a long waiting list. Title VII part B is not available to anyone who is eligible for services under the Massachusetts Rehabilitation Commission, and must be the last choice for funding.

Hear Now (HN)

Hear Now, a non-profit program of the Starkey Hearing Foundation, provides hearing aids and cochlear implants to eligible individuals with limited financial resources. Hear Now coordinates a national hearing aid bank and accepts hearing aid donations from people all over the country.

Services for Senior Citizens

In addition to the support mentioned earlier in this chapter and the skills, options, and devices we speak of in later chapters, late-deafened seniors may want to check out the following resources:

Deaf Senior Citizens Centers

These provide social, cultural, recreational and educational activities for deaf seniors in the Commonwealth. See the Appendix for a list of centers.

New England Home for the Deaf

A self-care facility for elderly deaf and deaf-blind people.

Gallaudet University Elderhostel Program for Deaf Senior Citizens

Offers accessible weeklong programs during the summer.

3. COMMUNICATION OPTIONS

“Let me put my glasses on so I can hear you” may sound like a joke, but it’s not. When our ears fail us, we come to rely more on vision. In this chapter, we’ll talk a bit about some of the communication options open to late-deafened folk. In Chapters 6 and 7, we’ll discuss assistive technology and high- and low-tech auxiliary methods of communication. Each of us develops unique ways of dealing with communication situations. No single method works in every circumstance, or for everyone. The more tools you have, the easier the task becomes.

■ Speechreading (also known as lipreading)

If you recall my own story, I wasn’t even aware of my hearing loss until it had reached a fairly advanced stage. How was this possible? Apparently, I had unconsciously learned how to speechread — to use lip movement, facial expression, and body language to understand the spoken word. This is very common. Most people, even hearing people, already speechread to some extent, for example, in noisy places. I remember two girls in my fourth grade class who could carry on a conversation from opposite sides of the room without using their voices. Many people who lose their hearing at a young age are phenomenal speechreaders. Speechreading, however, certainly isn’t a cure-all. Many sounds look the same on the lips or are invisible; only about 30% of all speech can be identified from lip movement alone. So how do we get the other 70%?

- Residual hearing: I, for one, make good use of the little that is left of my hearing. Any little piece of the puzzle helps. It’s amazing how much we can derive from the smallest clue.
- Context: We can expect to hear certain words in certain situations. If I’m talking about Tiger Woods, the pro golfer, I might expect to hear the words birdie, par, fairway, putt, among others. If I’m in a restaurant, I might expect the waitress to tell me about the soup and vegetable of the day, what salad dressings are available, or ask if I want my hamburger well done or medium rare. Knowing the topic lets us guess far more accurately. This is one reason why many of us have such a difficult time when a speaker changes the subject unexpectedly. You would not, for example, expect an archeology professor lecturing on the excavation of Troy to mention mutual funds or the Beatles.

- Body language and facial expression: Few people talk with a completely wooden expression. A raised eyebrow, a pout, a shake of the head all give us clues that we can use to help understand conversation.
- Our intuitive knowledge of the language (“collocation”): Some words keep company with other words. Having grown up in the hearing world, we are attuned to the grammar and rhythm of the language, common phrases, the way words are assembled in English. We know, for example, that fairytales often begin Once upon a time, that people set out to do things, make a dash for their vehicles in a sudden downpour, that events move toward a conclusion, and all’s well that ends well. If we get even a few hints from speechreading, our brains can usually fill in the gaps. It’s a bit like doing crossword puzzles.

“Despite the fact that I am continually confronted by mumblers, I can usually communicate with anyone, using my speechreading skills and communication strategies — providing the other person has a pair of lips, a set of teeth, and does not speak in Swahili,” writes Barbara Liss Chertok of Florida, who lost her hearing at 21 as a result of a virus and now teaches speechreading in Maryland.

But, speechreading, especially if you are totally deaf and relying completely on visual cues, is very difficult and calls for intense concentration. Mustaches and beards, accents, sloppy speech habits, chewing gum and smoking are all major challenges to speechreading, as are group situations and lectures delivered from a raised platform. At the end of the day or if I’m sick or tired, I sometimes don’t have the energy to speechread with much success. It’s hard work, so it’s important to try to make it easier. Remind the speaker — repeatedly if necessary — to face you when speaking. If possible, position yourself so that you are near the speaker and on the same level. To avoid shadows or light glare, light should be behind you or from the side, and should fall on the speaker’s face. If, on the other hand, you’re using signed English support to augment speechreading, you’ll want to stand back a bit so that you have a wider visual field for all visual-gestural-behavioral clues. Ask the speaker to remove hands, pipe, gum, microphone, or whatever may be hiding his or her lips. I even have a doctor who asks me to call a few days before my appointment so that he can trim his mustache!

How do you learn to speechread? You can try to teach yourself from

books and videos, but it's far easier to take a class. You really need to be able to practice with a teacher, particularly if you don't have much (or any) residual hearing to provide additional clues. The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) can refer you to speechreading classes. You can also practice with friends or family. As with everything else, some people catch on faster than others. And some people are easier to speechread than others. If you don't like to guess unless the odds are very much in your favor, you may have difficulty; speechreading requires a lot of guessing and some leaps of imagination. Remember that in everyday conversation, you don't have to understand every word to be a successful speechreader.

Speechreading has its pros and cons:

Pro: All of us have some existing speechreading skill and even a few speechreading lessons may help significantly.

Con: Demands total concentration, since many sounds look the same on the lips. Very difficult in groups or if the speaker is far away, has facial hair, an accent, wears tinted glasses or sunglasses, or doesn't move his or her lips. Doesn't work at all in the absence of sufficient lighting, which is a distressing hallmark of many social situations and events.

American Sign Language (ASL)

Wherever there are deaf people, there has been and will always be a sign language because it is a visual language. American Sign Language has its roots in the early 1800's. In 1815, a young seminarian named Thomas Hopkins Gallaudet went to Europe to study teaching methods, funded by a group of Connecticut businessmen, with the intention of founding a school for the deaf in Hartford, Connecticut. In France, he studied French sign language with Abbé Sicard before returning to this country with Laurent Clerc, a deaf Frenchman. Clerc became the first teacher of the deaf in America. ASL has many borrowings from French sign language as a result, but it has its own idiomatic usage. The school Gallaudet and Clerc founded in Hartford became the first residential school for the deaf in the country, and continues to this day as the American School for the Deaf. Gallaudet's son, Edward Miner Gallaudet, went on to found what is now Gallaudet University in Washington, D.C., the only university for deaf students in the world.

American Sign Language is the primary language of the Deaf community in the U.S.; deaf users of ASL are thought to number about half a million people and the number of hearing people who become ASL fluent is growing. Some Deaf people use ASL exclusively, but most are bilingual and use English and ASL. ASL is not simply a miming of English; it is a complete language with its own grammatical structure. Hand and body position, and orientation, as well as facial and body expression all occupy a place in the grammatical structure of ASL. ASL does not have a one-to-one relationship with English. Although it is distantly related to French Sign Language, it continues to evolve as do all languages. Like many other spoken languages, including Native American languages and indigenous languages in Africa and Australia, ASL has no written form for everyday use. Also, ASL is not universal. Almost every country has developed an indigenous form of sign language, so that even Deaf citizens of neighboring countries can have considerable difficulties communicating with one another at first. Similar to Esperanto (created as a universal language for everyone), there is also an "artificial" universal sign language that is used at World Federation for the Deaf events.

MCDHH keeps an updated information sheet on Sign Language classes in the state. Many colleges, organizations, Independent living centers, and adult education programs in Massachusetts offer courses in ASL. The Massachusetts State Association for the Deaf (MSAD) also offers classes across the state. There are a number of books and videotapes available to supplement interactive classwork. Many hearing people take ASL classes because they have family members or friends who are deaf or severely hard of hearing. Many other hearing people study ASL out of a fascination for the language. The best way to learn ASL is from a deaf person who is a fluent signer. As with learning any foreign language, you'll have to practice, practice, and practice some more. If possible, try to attend some Deaf community functions. It's a very interesting and eye-opening experience to feel at first like you are in the minority, unable to communicate easily. Many Deaf individuals are bilingual or even tri-lingual, and will readily help the beginner with sign language.

Pro: A full language, with an inherent beauty. Fully visually accessible and enables use of ASL interpreters and Signed English transliterators. Even a beginning knowledge of ASL will begin to facilitate participation in the Deaf community, many of whose Deaf members

happily welcome people who are interested in learning their language. Many community events are interpreted and therefore visually accessible.

Con: Like any foreign language, may take years to acquire fluency and requires much practice. Use of facial expression and body language is sometimes difficult for English speakers. Its usefulness to you may depend somewhat on how many of your family, friends, and hearing associates know it or are willing to learn it.

■ Fingerspelling

Every late deafened person should learn fingerspelling. It's a lot handier than using pen and paper when you are with other people who know it. Fingerspelling is taught in all sign language classes.

American fingerspelling is a system of shapes made with a single hand (the fingerspelling of Great Britain, Australia, and some former British Empire countries uses two hands) that correspond to the letters of the alphabet. Signers use fingerspelling for names and to spell out special words (scientific terms, names of corporations, such as IBM, for example). It's especially useful for unfamiliar names and addresses. Friends and family of late-deafened people often learn fingerspelling and find it extremely useful for indicating changes of subject in conversations or for supplementing speechreading for difficult words. Although learning the fingerspelled letters may be easy for some, reading and using fingerspelled words takes practice. Experienced signers can fingerspell with breathtaking speed.

Pro: Easier than carrying around a pad and paper. Extremely helpful for spelling out names and difficult words. Practiced users fingerspell very quickly.

Con: Needs lots of practice to learn to use with speed. Receptive skills often lag behind.

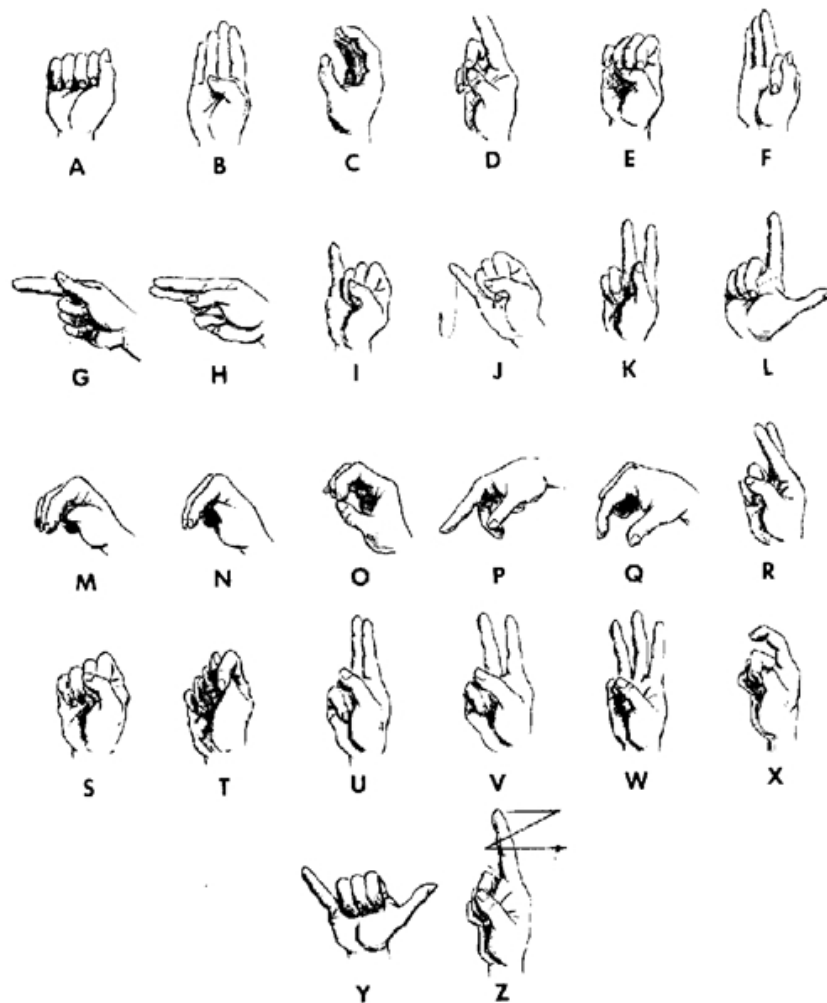
3

COMMUNICATION OPTIONS

■ Signed English and Its Variations

Various systems of manual English have been created to provide deaf and severely hard of hearing users with visual support for speechreading English. Many late-deafened adults whose first language is English find signed English easier to learn and use than ASL. They are attracted by the fact that they can simultaneously speak and sign the primary English words in sentences. Visual signs help the speechreader fill in the information for the "missing 70%" of speech sounds which cannot be seen on the lips.

FINGERSPELLING ALPHABET



There are several signed English systems that attempt to parallel spoken English with signs for speechreading support. All signed English systems, all forms of manually coded English, use spoken English and signs simultaneously. All use ASL signs to some extent; some systems also use non-ASL, “invented” signs for many words. And some systems use invented signs for English markers, such as plurals, suffixes, past tense, pronouns, and so on. The two main terms you will hear are:

- **SEE** (Signing Exact English): SEE borrows many word-signs from ASL, uses some invented signs for words and also for grammatical markers (prefixes, suffixes, past tense, plural, etc.). Such a complex system is often very cumbersome to produce manually within the natural flow of speech and to process visually.
- **Forms of Signed English** use spoken English and English structures with ASL signs to parallel spoken (or mouthed) English. It tends to use fingerspelling considerably to “fill in” articles, sometimes pronouns, and other words. Some forms of Signed English also may use invented signs. Signed English is visually complex and hence somewhat cumbersome to produce, especially while simultaneously speaking. It is much harder to process visually than ASL.

Pro: Easier for some late-deafened and hearing people to learn than ASL since it uses English word order and grammar and relies less on facial expression. Possible to speak and sign simultaneously, thus making speechreading easier by supplying the “missing 70%” of speech sounds.

Con: Not a language. Cannot completely parallel English. Hard to maintain the flow and normal pace of the spoken language while simultaneously signing English. Because it uses the grammatical structure of English as its base, it is not structured (as ASL is) to accommodate visual reception and memory.

Another term that you may hear is Pidgin Sign English (PSE). PSE is a mix of signed English and ASL, in much the same way that Creole mixes French and English, borrowing from both languages to facilitate communication between two speakers, neither of whom is fluent in the other’s language. PSE generally employs some structures and idioms of ASL and uses some mouthed/spoken words of English. It is often the result when a Deaf person who is fluent in ASL and a hearing person who signs but is not fluent in ASL attempt to communicate. Each makes some accommodations to the other. Depending on the users, PSE can lean more towards “the ASL side” or more towards “the signed English side”.

■ Cued Speech

Prof. R. Orin Cornett of Gallaudet University developed Cued Speech in 1966 to make the sounds of spoken language visible. For some people, cueing can be an aid to speechreading, helping clarify the sounds that look the same on the lips (such as B and M), sounds that aren't really visible on the lips (such as K and G), and vowel sounds. To use a wonderfully clumsy audiological term, cueing "disambiguates" sounds.

Cued speech is relatively easy to learn. Eight handshapes used in four different positions near the face signify different sounds. To cue, one must learn to think in terms of sounds. For example, there is no handshape for C; in English, it is either an S or K sound. This can be a difficult adjustment to make. Since Cued Speech is based on sound, you can cue any word you know how to pronounce. For some users, it's been very helpful in learning foreign languages.

Cueing hasn't really caught on. Cued Speech transliterators, as they're called, are few and far between. Activity in the state seems to be centered at the Massachusetts Institute of Technology in Cambridge. A group in the Sensory Perception Laboratory there is developing an "Autocuer," a machine that can generate cues as someone speaks. Practice Cueing sessions, open to the public, meet once a month on campus, and Jeanie Krause, a former graduate student in electrical engineering, has created a number of Web pages describing Cued Speech.

Pro: Easier to learn than ASL or Signed English. Presents a complete visual picture of the speech sounds of English, including information not provided by speechreading.

Con: Few people use it. Requires that we think of words phonemically (based on the sounds the letters make) rather than on how the words are written or spelled.

Which Should I Choose?

There is no "one size fits all" answer. However, many of us agree with the communication philosophy of the Association of Late-Deafened Adults: "whatever works."

All of us who have become deaf or acquired a severe hearing loss have spoken English as our primary language. Speechreading is very important, and any technique that supplements speechreading

is valuable. I personally think that anyone who is late-deafened or hard of hearing should first have some instruction and practice in speechreading and fingerspelling. Even if you don't become expert, you'll still find these skills increase your ability to understand the spoken word. Whenever we can pick up more clues to conversation, it makes the task of understanding easier.

From a practical point of view, you will probably want to learn whatever language is used by the people with whom you communicate most frequently. But even if that language is not ASL, you might still want to learn it (or signed English) to add a new dimension to your communication versatility. Many late-deafened people who have learned ASL enjoy participating in the social, political, and community activities of the Deaf community while maintaining important relationships with their family, friends, and co-workers in the hearing world. Many of them have found interesting Deaf friends and have been able to choose jobs in which they work with other Deaf and late-deafened people.

In addition, ASL automatically gives you a vocabulary for Signed English and you can easily make the switch to manually coded English. Fluency in ASL or signed English also gives you access to ASL interpreters or Signed English transliterators, which can be a great convenience, since they are so widely used and relatively easily available.

When analyzing your communication needs, I think you have to ask yourself a few questions. First and foremost: will learning another skill help me?

- Look at your work situation. Do you work in a large office or are you a consultant working from home or in an office of your own? Do you spend time in a classroom situation, as a student or teacher? Do you travel? Attend meetings or lectures? Use the telephone for business? Would your co-workers be willing to learn a new language or skill to communicate better with you? Would the ability to use interpreters be useful?
- Look at your home life: Would your family and friends be willing to learn a new language or skill in order to communicate better with you?
- What about your community? Are there any other people who use sign language or want to learn it?

- Do you have the time, resources, opportunity, and motivation to invest in learning new skills and/or languages?
- What kind of person are you? Are you outgoing or shy? Do you enjoy learning new skills and meeting new people?
- How good is your vision? Is speechreading a realistic possibility?
- What are your entertainment likes and dislikes? Do you enjoy dining out? Partying? Attending plays and movies? Outdoor activities? Intimate or large groups?

I'm sure you can think of further questions, but this is a good start.

4. COMMUNICATION SKILLS

As soon as you recover from the initial shock of becoming deaf, your first priority should be to start to deal with “The Communication Problem.” Because learning new ways to communicate is time-consuming, it’s a good idea to start by making the most of what you already have. You’ve probably always taken speaking and listening for granted. Now it’s time to take a closer look at communication strategies and do some problem solving. You’ll find that there are a number of factors that you can control.

■ Letting People Help You

One of the most difficult adjustments to make is to learn to ask people to work with you to optimize communication. Most people have no idea how to communicate with a deaf person. You’ll have to teach them. And when you’re finished, you’ll have to repeat what you said, and repeat it again. Changing speaking habits is very difficult. Asking people to change is also difficult. Have patience, ask politely, smile a little, use a little humor. Both of you benefit when your communication needs are met.

- **Be honest.** Tell people that you’re deaf. If you’re having trouble with the d-word, re-phrase it. I often feel that using it with certain people will upset them — I’m not quite sure how to react to stunned silence, embarrassment, or “I’m sorry” — so I sometimes just tell people that I have a profound hearing loss or am “very hard of hearing.” It doesn’t matter what you call it as long as you get your point across.
- **Resist the urge to bluff.** It’s far more difficult to tell people you’re deaf after listening to them speak for 15 minutes and not understanding a word. A little later in this chapter, we’ll discuss strategies to use when you don’t understand the speaker.
- If background noise is a problem, try to find a quiet corner with good lighting. If possible, turn off the television or radio or other source of background noise.
- Carry a pad and pen, just in case you get stuck.
- Ask people to face you when they speak. Let them know that you won’t hear them or even know that they’re speaking if they talk to your back or call to you from another room.

- Don't hesitate to ask speakers to remove gum or other objects from their mouths - and not to talk with their mouths full in the first place.
- Be polite but assertive about your communication needs. If you don't tell people how best to speak to you, they won't know. And once they know, they may forget and have to be reminded.

Every now and then, you'll meet someone who is rude or uncooperative. Try to find someone else with whom to speak. But if it happens frequently, it may have something to do with the way you're presenting yourself. Ask yourself: Am I being confrontational instead of reasonable? Impatient? Angry? Demanding? There's a big difference between being assertive and being aggressive. Or maybe I'm not being assertive enough? Communication is a joint enterprise. Treat your "partner" with consideration.

Changing the Environment

Have you been wanting to redecorate? Here's your chance. Start by analyzing where you normally sit during the day: at meals, when entertaining, when relaxing. There are a number of things you can do to improve the environment for communication.

Carpet and wall covering: Sound bounces off bare floors and walls, so if you have residual hearing, you may want to make changes in wall and floor covering. When I first stepped into my new condo, a converted school with 10 foot high ceilings, every word seemed to echo. Since unpacking, the situation has improved dramatically, but I could further improve it by adding a rug, draperies, wall-hangings and pictures.

- Rearrange furniture: It's important for you to be able to see the speaker's face without straining. Place your favorite seat so that the light isn't in your face and so that it's opposite where guests or family members usually sit. If you're speechreading, you'll want to sit fairly close to the speaker. If the speaker is signing, you'll want to sit a bit farther away, to widen your field of vision.
- Position yourself so that you don't have to crane your neck. If the speaker is sitting, sit. If the speaker is standing, stand. If the speaker is a Boston Celtic, find a ladder!

- Make adjustments as you go along at home, at work, and when visiting. People will understand if you close blinds in back of them so that you aren't looking into the sun, or move lamps, remove vases from tables, move a chair. Just explain what you're doing and why.

■ Dealing with Difficult Situations

In Chapter 9, Real Life Coping, we'll have suggestions for specific communication situations such as church, meetings, and lectures. Here, we'll just list some of the strategies you can use if you don't understand what someone says.

One of the simplest but most difficult things you can do is to get out of the "What?" habit. Sometimes, it takes the brain a fraction of a second to figure out just what the speaker has said. Most of us are guilty of asking "What?" the instant the words are spoken, only to figure out the meaning, in many cases, as the speaker begins to explain.

- **Rule #1:** Give the brain a split second before asking for an explanation of something you didn't hear.
- **Rule #2:** Don't say "What?" "Huh?" "I didn't get that," "Please repeat that," etc.
- **Rule #3:** Don't interrupt the speaker in mid-sentence. The second part of the sentence may give you the clue you need to understand the beginning.

"What?" and its variations are a bit too open-ended to be useful. The speaker is left wondering exactly which part of the conversation you didn't understand and tends to repeat the entire sentence (or more), which may not be necessary. Try to be more specific when you request information. Sometimes, repeating back part of the sentence helps. If anything, such attention to what the speaker is saying is considered flattering by many individuals, so don't worry about being politely inquisitive.

When the speaker says, "Janie graduated from Abbey Meadow Pre-School last Wednesday." Don't say, "What?" Instead, try:

- "Who graduated?"
- "When did Janie graduate?"
- "What school was that?"

When you receive important information, be sure to confirm it. Most of us have shown up for appointments at the wrong time or even the wrong day, misunderstood directions, and such. Everyone does this, not just late-deafened people, but it's more likely to occur when you're deaf. So, for example, tell the secretary, "Let me confirm this. I have an appointment with Dr. Jekyll next Tuesday, July 15th, at 10 a.m. And I shouldn't eat or drink anything after midnight. Correct?"

Ask the speaker to re-phrase what he is saying or write down the key words or numbers. If you have residual hearing, you can ask for the correct spelling of a word or name you don't understand, for example, "Was that B like in Balcony or P like in Petunia?" Be patient, with the speaker and with yourself. When you're totally exhausted and having difficulty giving the speaker the concentration that is necessary, excuse yourself and take a short break. At social gatherings, you can control the situation a little bit by asking your conversational partner if he or she wouldn't mind finding a quieter place to speak, because you REALLY want to hear what they have to say but just can't in the current environment. If you become overwhelmed by the environment and you're with friends, just explain that you're taking a break, that they should continue whatever they're doing, and that you may ask for a summary or clarification later on.

For Hearing People: How to Communicate with a Deaf Person or a Person with a Hearing Loss

- Ask the deaf person what you can do to make communication easier.
- Make sure you have the person's attention before you speak.
- Face the deaf person. It's important for him or her to be able to see your face.
- Be aware of background noise and try to find a place to talk that minimizes it.
- Pick a spot to speak where the light, artificial or natural, is not behind your face since it makes speechreading more difficult.
- Remove any objects from your mouth that might interfere with speechreading: gum, food, etc.
- Speak clearly and enunciate, especially if you have the proverbial stiff upper lip.
- On the flip side, don't overemphasize lip movements. It will make speechreading more difficult, not easier.
- Don't shout. If the person has no hearing, it won't help. If the person has some residual hearing and wears hearing aids, it will only distort what you say, not to mention the embarrassment created for the both of you when everyone turns to stare.
- If the person doesn't understand what you have said, don't just repeat it. Re-phrase it.
- Try to give the person some indication when you change the subject.
- Make sure that only one person talks at a time.
- Recognize that speechreading and listening involve intense concentration for late-deafened people and can be very tiring.

For your part, it's important not to forget just how difficult it is to change deeply ingrained speech patterns. We've already mentioned it, but it bears repetition: Be patient with people and keep your sense of humor.

5. HEARING AIDS AND COCHLEAR IMPLANTS

Even a mild hearing loss can interfere with your ability to understand speech and use the telephone. If you wish to remain a full participant in the hearing world, you'll probably want to check out the possibility of using hearing aids. In more severe cases of hearing loss, a cochlear implant may be in order. We'll discuss both in this chapter. Technology is rapidly changing, so you'll want to stay abreast of new developments by doing some research before committing to either device.

Hearing Aids

Many people have some strange ideas about hearing aids. They equate them with eyeglasses and think that all we have to do is put them on and our hearing will be miraculously restored. Unfortunately, that isn't the case. Although there have been some real advances in hearing aids in the last few years — miniaturization, digitization, computerization, features such as programs to constantly sample environmental sounds and adjust the volume accordingly, and frequency filters to minimize unwanted background “noise” — the essential problem of hearing aids remains: they can't distinguish between sounds that we don't want to hear and sounds that we do want to hear. And, unlike ears, hearing aids are not omnidirectional, so it's difficult to locate where sounds are coming from. Nevertheless, if you have some residual hearing, you will probably want to see if there is a hearing aid that will help you, if only to let you monitor the sound of your own voice, hear environmental sounds, and reduce the levels of stress and fatigue that you experience from straining to listen.

From left to right:
CIC, ITC, ITE, two BTE's



Styles of Aids

We've come a long way since the ear horns of yore. There are ten main styles of hearing aids:

- **Behind the Ear (BTE) aids:** These consist of an earmold that fits into the ear canal and most of the outer ear, connected by a short plastic tube to an aid that sits behind the ear. BTEs are most common for people with severe to profound hearing losses, but are useful for all other types of hearing losses as well. One of the advantages of BTE aids is that it's easier to get a loaner aid if yours needs repair. You simply attach your earmold to the replacement aid and you're good to go. Another, often overlooked advantage, is that the size of the hearing aids makes adjusting controls and replacing the batteries much easier for people with vision problems, arthritis, or fine motor control issues
- **In the Ear (ITE) aids:** The entire hearing aid fits inside the outer ear. Although there are a few powerful models, most are for moderate rather than severe to profound losses.
- **In the Canal (ITC) aids:** These fit completely inside the ear canal and are mainly for mild to moderate losses.
- **Completely in the Canal (CIC) aids:** These tiny aids fit deep in the ear canal and are removed with a stem of wire. They usually have an automatic volume control because there is no room for manual controls. Their size is a major issue for anyone with less than superb manual dexterity - and if they are dropped, finding them becomes a real chore.
- **Open Fit Hearing Aids:** These aids, a variation on Behind the Ear aids, have become extremely popular in the last few years. Devised to prevent occlusion, the unnatural amplification of your own voice and the stuffy feeling that earmolds often engender, they are particularly suited for high frequency losses. Thin tube models are like BTE's that replace the regular tube with a far thinner tube and the earmold with a silicone dome that comes in several sizes. The Receiver in the ear (RITE), also known as Speaker in the Ear (SIE), models have a wire inside the thin tube; this "floats" in the ear canal, held in place by a thin wire in the bowl of the ear. In addition to their use for high frequency losses, they can also be programmed for more severe losses. Because there is no need for an earmold with these aids, fitting can be accomplished in a single office visit.

- **Body aids:** These have cords going into earmolds, but the hearing aid is contained in a unit the size of a deck of cards, which is hung around the neck or fastened to a chest strap. Used by a small number of profoundly deaf adults and also by young children who might lose or damage more delicate aids.
- **CROS (Contralateral Routing of Signal) aids:** These are for people who have no hearing in one ear and usable hearing in the other. The components resemble nothing so much as two behind the ear aids, but the one draped over the “bad” ear has no earmold, and instead contains a wireless microphone and transmitter or a cord to route sound to the other, “better” ear. This eliminates the “blind spot” caused when someone is talking on your “bad” side by transmitting the sound to your “good” side.
- **Bone Conduction Aids:** Some hearing aids use bone conduction of sound vibration. The hearing instrument is connected to a headband that has a small thumbnail sized oscillator (vibrator) positioned against the bones of the skull to transmit vibrations to the listener.
- **Bone-Anchored Hearing Aids (BAHA):** This type of aid also operates by bone conduction, bypassing the middle ear and transmitting sound directly to the inner ear. A titanium post is implanted behind the ear in a minor surgical procedure. The sound processor snaps onto this post. This aid is useful for those with chronic ear infections, a congenital hearing loss due to malformation or absence of the outer ear or middle ear (known as atresia), or for unilateral deafness.
- **Eyeglass aids:** The sidepieces of these heavy plastic glasses hold the aids. These were popular in the 1950’s through the ‘70’s, but a new model, which includes directional microphones in the sides of the frame, has now been developed by Varibel, a Dutch company, and is available in Europe. The obvious drawback here is that you may still want to hear when you take off your glasses, which becomes impossible using this type of aid.

In addition to these major types of aids, there are a host of others: solar-powered aids, earring aids, and probably most important, implantable and partially-implantable hearing aids, such as Otologic's Carina and Med-El's Vibrant Soundbridge.

Audiologists usually recommend getting hearing aids for both ears.

Analog vs. Digital

Hearing aids come with two main types of circuitry: analog and digital. Industry statistics indicate that at this writing, nearly 90% of all hearing aids use digital technology, in which sound signals are converted to binary form that can be processed by a computer chip.

There are still a number of analog aids on the market, though. These are less expensive than digital aids, and less versatile, but they may be all you need. This is particularly true for individuals with severe to profound hearing losses. Many of them report that analog hearing instruments are more suited to their needs than digital aids. Analog programmable aids are capable of holding multiple programs in memory. You might, for example, have one program for noisy situations, one for quiet environments, and one for the telephone.

Digital aids are the most expensive and have the most sophisticated capabilities. A good audiologist experienced in programming the particular aid can make adjustments at different frequencies to give you the most benefit from amplification, as well as multiple programs for various situations.

How to Buy Hearing Aids

When you lose all or part of your hearing, your first consultation should be with a doctor specializing in hearing loss (an otologist, otolaryngologist, or ENT [ear, nose, and throat] doctor). You need to find out if your loss is caused by something that is medically or surgically treatable - for example, something as simple to "fix" as an ear wax buildup may block sound from traveling through the ear canal and effectively render you "deaf." As part of the examination, the doctor will send you to an audiologist, who will test your hearing. Your audiogram shows what frequencies of sound you are able to hear at what volumes; other supplementary audiological tests show how well you understand (discriminate) those speech sounds under various conditions and at different levels of amplification. If you have absolutely no residual hearing, the process ends right there. A hearing aid will do nothing for you if you have no hearing left.

If hearing aids are a possibility, your next destination is the office of a hearing aid dispenser or dispensing audiologist. This is the person with whom you will work to select, modify, and fit the appropriate hearing aid or aids to accommodate your hearing loss and your lifestyle. The dispenser will also introduce you to the use of the aids and instruct you in their care and handling. Select a hearing aid dispenser with care since this is the person with whom you will work very closely. To find a hearing aid dispenser, get a referral from the doctor, a friend who has succeeded with hearing aids, a clinic, or a reputable organization. If at any time you feel you are being given a “hard sell” - the hearing aid instrument specialist or dispensing audiologist seems to be aggressively pushing you towards a particular brand or model and telling you that “this is the only hearing aid for you” - run, do not walk, to the exit. There are dozens of manufacturers and dozens of models by each manufacturer. You would not think of shopping for a car by buying the first car from the first salesman you see; regrettably that is exactly what most hearing aid shoppers do. At least do some comparison shopping like you would do with any other product, and do take into account the professionals’ demeanor towards you and their willingness to answer even difficult questions.

On September 4, 1998, Governor Paul Cellucci signed Chapter 321 of the Acts of 1998, which called for the establishment of a Board of Registration for Hearing Instrument Specialists. With the passage of this law, Massachusetts joins 48 other states that have a state licensing process for hearing aid dispensers. The new hearing aid law sets minimum standards for entry into the field and also sets enforcement standards for violations of practice, ethics, or unlicensed practice. As of July 1, 2000, all hearing aid dispensers in the Commonwealth must be licensed as audiologists or by the Board of Hearing Instrument Specialists.

- A dispensing Audiologist has a master’s or doctoral degree. Audiologists specialize in the diagnosis, evaluation, and management of hearing loss and have extensive training in hearing loss and rehabilitation. In addition, they have passed a certification exam and hold a credential from the American Speech Language and Hearing Association (ASHA)
- A Board Certified Hearing Instrument Specialist has training in fitting and dispensing hearing aids, has taken an exam and

holds a credential from the National Board for Certification in Hearing Instrument Sciences.

- Some individuals who sell hearing aids hold no credentials. Such individuals may or may not have had appropriate training through courses and/or apprenticeships; generally speaking these should be last on your list because there is no way for you to measure their success rate.

In addition to considering the qualifications of the hearing aid dispenser, you want to buy your aids from someone who:

- carries a number of different brands and models, not a franchise operation that only has one brand of hearing aids
- will spend time answering your questions and coaching you in the use of the aids
- will give you a reasonable trial period to use the aids, at least 30 days and possibly more, and has a reasonable return policy if you find the aids are of little use or if you want to try another model. Jonathan O'Dell from MCDHH often encourages consumers to "push" for an extension of the 30 day trial period at time of purchase, and to do so in writing. This extension goes into effect if, at any time during the first 30 days, the hearing aid has to be readjusted. Since that essentially means the hearing aids weren't adjusted optimally for whatever period of time you had them, you should be given a full 30 days to see if they will work for you once they have been optimally adjusted.
- will be able to offer you a loaner should your aid need to be repaired
- is familiar with ALDs (assistive listening devices, which we'll discuss in the next chapter) and knows how they work with certain hearing aid options

Fitting hearing aids is both art and science, particularly for a severe to profound loss. This is because hearing loss is a very complex business. If it were only necessary to crank up the volume, then it would be a simple matter, and Uncle Al, who always yells at you, would be very easy to hear. 'Tain't so. For one thing, the amount of amplification usually has to be different at different frequencies,

since most of us don't have the same loss at all sound frequencies. Second, many people with sensorineural hearing loss cannot tolerate loud noises (this is called recruitment) and can hear comfortably only within a very narrow range of amplification. But the main roadblock is that hearing loss consists of more than a simple need for amplification. The way the brain interprets sound is the other half of the picture, and much of it remains a mystery. Two people with the exact same audiogram can have very different comprehension abilities. One may be able to discriminate speech sounds with a fair degree of accuracy. The other person, with poor discrimination, will hear noise rather than words.

A good hearing aid dispenser has a lot of tricks up his or her sleeve: venting the earmold, making it from different materials - also something to consider if you have any specific allergies -- changing the diameter of the eartube or earhook, and making adjustments to the way the hearing aid amplifies sound. All this is to say that ears do not always behave exactly the way tests predict. And, as Dr. Mark Ross, professor emeritus of audiology at the University of Connecticut and himself a hearing aid user, has mentioned, no hearing test currently even attempts to measure the stress of hearing.

Richard Rosenthal, author of **The Hearing Loss Handbook**, published in 1975 (and not to be confused with the book of the same title published more recently by **Consumer Reports**), tells of how he was interviewing a professor of otolaryngology (an ear, nose and throat specialist) at a New York medical center. The surgeon, noticing that Rosenthal was straining to hear him, snapped, "Why the hell don't you get a hearing aid?" "I replied that a whole host of doctors and audiologists had unanimously and recently told me that I did not need an aid or could not benefit from one," wrote Rosenthal. "'Horsefeathers [sic],' he replied. 'Forget them. Get a hearing aid.' I did. It helped immediately," reported Rosenthal.

When considering the purchase of hearing aids, there are several factors you should take into consideration:

- Your lifestyle: Are you a social butterfly or a homebody who is happiest in his/her own four walls? Do you participate in many social events, or do you spend most of the time happily reading or watching television with closed captions on, and taking solitary walks in the park? If you very rarely go out and have a mild hearing loss, you may not even need a hearing aid. Some

people will function wonderfully using assistive listening devices which can be hundreds, if not thousands, of dollars less than hearing aids.

- Do you have a very active lifestyle and if so, is perspiration going to be a factor? Moisture is the biggest enemy of any electronic device, including hearing aids.
- How is your manual dexterity? Smaller hearing aids take tiny batteries, difficult to change even with some of the newfangled self-dispensing battery packs. Will you be able to insert a miniature hearing aid yourself or will you need assistance?
- How good is your vision? If your aid falls on the floor, will you be able to find it? Some of the smaller aids are tiny and can easily get lost in a shag carpet or fall into a floor register. If you have pets, you also have to worry about a pet finding it before you do, in which case your hearing aid may be consumed with great relish - yet another reason to buy specialized hearing aid insurance.

There are also several features that you should demand.

Telecoils (aka T-Switch or T-Coil)

Never buy a hearing aid that doesn't have a telecoil. This is a bit of electronic circuitry (a small spool or coil of wire) that lets the hearing aid pick up electromagnetic energy from another telecoil found in a sound source such as a hearing aid-compatible telephone receiver, and convert it back to amplified sound. Since 1989, every corded telephone sold in this country has been required to be "hearing aid (telecoil) compatible." Telecoils vary greatly in effectiveness, like the old rabbit ears on televisions. You should ask your hearing aid dealer to make sure that the aids you buy have powerful telecoils. To activate the telecoil, adjust the switch on your aid to the T setting; you'll probably have to increase the volume setting on your aid, too. Position the external telecoil (the one in the telephone handset, for example) close to the internal telecoil of the hearing aid until you receive a clear signal. The sound may be somewhat different from what you hear on the microphone setting. Using the telecoil not only prevents the feedback (whistling) that you may get using the microphone setting; it also eliminates all background noise because the "T" setting usually disables the external microphone (some hearing aids do have a setting allowing the mike and the "T" coil to be on simultaneously). Telecoils are also extremely important because they

let you use some of the assistive listening devices and systems we talk about in the next chapter. Some aids that do not have telecoils can be retrofitted with them, for a fee -- if there is room available inside the instrument to do so. This is one excellent reason to get a BTE, open fit, or ITE aid. Smaller aids may be “invisible,” but they cannot accommodate telecoils.

Direct Audio Input (DAI)

Some hearing aids come with, or can be retrofitted with, a direct audio input to the hearing aid's amplifier by means of a multipin cable, (DAI) jack, or coupled via a DAI shoe or boot. DAI lets the aid make a direct connection to any audio output, such as a radio, microphone, tape recorder, television, or assistive listening device, bypassing the hearing aid microphone. Using DAI eliminates background noise, since the aid connects directly to the desired sound source, which is a boon for noisy environments, or for people such as medical professionals who work in an area with ambient EMF (electro-magnetic fields) where the telecoil cannot be used because it would also pick up the “hum” of the EMFs.

Remember how we mentioned in the Introduction that if you had to lose your hearing, this was as good a time as any to do it? Among the reasons for this statement are the many new developments in hearing aid technology. Some of the more important ones are:

- Directional microphones, which allow you to “focus” on a sound simply by swiveling your head towards the sound source, and other advances in microphone technology.
- Digitization of sound: Most new hearing aids are digital rather than analog. Sound quality can be far better for people with mild to moderate hearing losses with digital aids. The digital models have built-in computer chips that let the audiologist program the aids with much finer adjustments than analog aids. However, as discussed earlier, digital hearing aids do not necessarily benefit everyone equally.
- Adjustable Programs: Digital aids, and programmable analog aids, are also capable of holding several programs for different situations. For example, you might have a program for noisy restaurants, one for telephone calls, and one for quiet.

- **Noise cancellation techniques:** Every manufacturer strives to improve performance of their aids in background noise. They use different techniques and make different claims. You'll have to try out the aids to see how they work for your ears. There has been much controversy in this field. Some users swear by noise canceling techniques, others are convinced they do not work at all. As in all things, the truth is probably somewhere in the middle, and very dependent on the situation one finds oneself in and what kind of background noise is present.

Adjusting to Hearing Aids

If you've never worn hearing aids before, you're in for a period of adjustment. Attitude is everything. If you don't want them to work, don't even bother to try them. That's what happened when, as a teenager, I tried my first aid, loaned to me by a university clinic. I didn't even have an earmold, just a universal earplug. I put it on, turned on a Joan Baez recording, listened for a minute, announced that I still couldn't hear the words of the song, and took the aid off. In my defense, no one had told me that listening to music was not the way to test out a hearing aid. But it could have made me hear like the Magical Helper of the folktale who could hear grass grow; and I still would have refused to wear it and would have found fault with it. I just wasn't emotionally ready for hearing aids and it was years before I would be.

People often think that they can put on the aids, walk out of the office, and hear perfectly again. The sad reality is that once you've gotten the aids, your work has just begun, a fact that bears repeating. Here are some tips for adjusting to hearing aids.

Start by wearing them several hours a day and build up. Earmolds can be very irritating. If yours is, go back to your hearing aid dispenser and ask to have the earmold or tube adjusted. If you experience an allergic reaction to the material of the mold, ask for a different mold made from hypoallergenic material.

Try the aids in different situations. Keep a record of your experiences so you can tell the dispenser how you've done when you return for a follow-up visit.

Have patience. Your brain needs time to learn to interpret the new sounds it hears. You need time to become comfortable with the aids. Recent research indicates this takes about 12 weeks.

Hearing Aids: A Recipe for Success

1. Wear the aids for several hours per day in a quiet environment to adjust to the new sound and to feel comfortable with the earmolds and manipulating the aids: inserting and removing them, adjusting the controls, etc.
2. Wear them in conversation with one or two people in a quiet setting, watching television, reading to yourself.
3. Wear them indoors in some minor noise: in the kitchen using an electric can opener, while running a fan in the bedroom, etc.
4. Try wearing them outside in a quiet area, then move to a noisier area. Wear them while driving, walking around a mall, in small groups.
5. Try them in the classroom or a large room, at church, talking to several people.
6. Experiment with adjusting volume and, if your aid is a programmable one, try changing programs in different situations.
7. Use the aid's telecoil (T-switch) and see if it helps you hear on the phone. You'll have to experiment with the position of the telephone handset on your ear, since the location of the telecoil varies greatly from model to model.
8. Wear them in a noisy restaurant or a party, but only after you've already done everything else. The surest way to disappointment is to leave your audiologist with a spanking new pair of hearing aids, and put them on that evening for a gettogether with old school friends you haven't seen in twenty years in a noisy, dim restaurant.

Vibrotactile Body-Worn Aids

Tactile aids provide a non-invasive alternative for late-deafened adults who are unable or unwilling to get cochlear implants and who seek support for visual speechreading. They can also work in conjunction with hearing aids (if used) to provide an impressive array of speech information not available from speechreading alone. These aids consist of a series of small vibrators mounted on a band that is worn across the chest or on the wrist or forearm. Sound is processed and sent to the vibrators. Tactile aids can alert the user to environmental sounds and help monitor speech production. They can also work in

conjunction with speechreading and hearing aids to “fill in the gaps.” Users can learn to identify a great deal of speech information from the location, intensity, and duration of the vibration pattern, for example, the explosive feeling of the P sound, the difference between the unvoiced F and voiced V, and the S at the end of a word.

Sadly, Audiological Engineering Corporation of Somerville, MA, manufacturers of the Tactaid® vibrotactile aid, has recently ceased operation, and no one is manufacturing such aids, which certainly had a role as inexpensive devices that benefited many profoundly deaf people. The cochlear implant, at the extreme opposite end of the cost spectrum, has completely supplanted the tactile aid.

■ Cochlear Implants (CIs)

The first wearable cochlear implant was developed by Dr. William House in 1969 to aid lipreading. It had a single electrode. Nine years later, Graeme Clark implanted a multi-channel device in a fellow Australian. In December 1984, the FDA approved the Australian cochlear implant from Cochlear Corporation for adults.



Cochlear Implant
Courtesy of: Med-El Corp.

The target audience for the first cochlear implants was people with severe to profound sensorineural losses (and intact auditory nerves) who received little benefit from hearing aids. In this surgery, an array of electrodes is implanted in the cochlea in the inner ear to stimulate the auditory nerve. A receiver is embedded in the mastoid bone behind the ear. Sound goes to a microphone worn on the head. It travels down a wire to a small box (the processor), which is worn behind the ear like a BTE hearing aid (or on a belt or carried in a pocket). The small computer in the processor converts the sound to electronic signals. These travel back up the wire to a transmitter held on the head by a magnet behind the ear. From here, the signals go to the embedded receiver in the ear, from which they then travel to the electrode array in the inner ear, where they stimulate the endings of the auditory nerve. At this writing, the FDA has approved implants from Cochlear Corporation, Advanced Bionics, and Med-El Corporation. All are excellent devices.

A cochlear implant is not a hearing aid; it's far more complex and very expensive. The cost of the device, surgery, and follow-up rehabilitation and fitting is around \$45,000-70,000, which may be covered by your health insurance, with or without a battle. Cochlear implants involve invasive surgery performed under a general anesthetic. Results vary greatly and are not really predictable. Surgeons differ on whether to implant the better or worse ear. A recent study at Johns Hopkins shows that it makes little difference, and the trend toward implanting both ears obviously guarantees that the better ear will always be implanted. People who have been deafened for a relatively short time seem to be the best candidates. Hospitals that perform implants put candidates through a wide range of tests before surgery, including psychological tests.

The incision takes about 4-6 weeks to heal, at which point the implant is connected to the processor, then turned on after programming. As with hearing aids, the sound that reaches the brain is far different from what we have been accustomed to, and the brain must "re-learn" how to hear. Many implant recipients report that initially, voices all sound like Donald Duck. "What if everyone, male and female, for the rest of my life, continues to sound like Donald with a speech impairment?" Paula Bartone-Bonillas remembers wondering. When my own implant was first programmed, speech sounded like chimes, but even in the first minutes, I received valuable timing information that helped my lipreading. Getting the most from the implant involves fine-tuning the processor program (the map) many times, and lots of work. Some implant users on the Beyond Hearing listserv report listening to the same song hundreds of times, gaining a little in understanding with each repetition. They may practice listening to books on tape and, in general, invest a great deal of time and effort into learning how to hear again. Many find the experience fun and exhilarating, marveling at each new sound. The success of the cochlear implant is a testament to the plasticity of the human brain, which can somehow convert the impulses from a handful of electrodes (up to 22 in some implants) to an approximation of the sound received by over 16,000 hair cells in an undamaged ear.

For years, many people in the Deaf Community vehemently opposed cochlear implants, particularly for children. They saw them as an assault on Deaf culture and American Sign Language. Everyone seems to agree that in an ideal situation, children would

be able to decide for themselves if they want an implant. The reality is that there is a short window during which children soak up languages readily, and the decision should optimally be made very early for the best chance of oral language acquisition.

The Academy Award-nominated documentary, “Sound and Fury” (2000), demonstrates this opposition and shows how the issue can split families. A follow-up by director Josh Aronson (“Sound and Fury: Six Years Later”) echoes the moderation of the position of the National Association of the Deaf (NAD) on the subject. The Deaf brother’s young daughter does eventually receive a cochlear implant, as do her mother, brothers, and several cousins; she functions capably in both Deaf and hearing worlds.

In the past, the acid test of a successful implant was whether the implant user could use the telephone. The focus has now shifted to music. Early implants were designed to maximize speech comprehension, but recent improvements in technology and mapping (programming) the processor now allow many people to listen to music with pleasure. Again, the key to success is continual practice.

Many users of current devices report some extremely impressive results, which bear fruit almost immediately. In 1997, Nancy Delaney called her decision to get an implant after almost 40 years of deafness caused by a childhood illness “the most courageous thing I have ever done in my life...but it certainly turned out well for me. I became a top performer during my second week of usage. I was using the phone by week #2 with limitations. I have progressed from there so that I can hear well without lip reading, even in moderate noise, I can hear music very well, use the phone with almost everyone.” Not everyone is such a star. Most people report steady progress over several years. Even those who receive the least benefit are usually able to hear environmental sounds, and find that the implant helps speechreading.

Since the first edition of this book in 1997, implants have improved dramatically. The incision made in the surgery has become smaller, the healing time has become shorter, and the requirements for qualifying for an implant have become far less strict. One need not have a profound hearing loss any longer to qualify for an implant. Most adult implants are now behind the ear models rather than belt-worn processors with ungainly wires. The number of channels has increased and mapping strategies have improved. Processors have

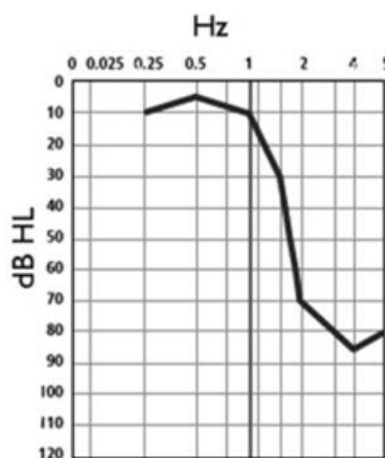
become waterproof to some extent, insurance companies are far more likely to pay for implants, binaural (both ears) implants are gaining in popularity, and battery life is increasing. Around 100,000 people have received cochlear implants worldwide.

What's the downside of cochlear implantation?

- Surgery is performed under general anesthesia, with the risks any such procedure involves.
- The surgery generally destroys the cochlea in the implanted ear, so you lose any residual hearing in that ear. As a result, users of traditional implants will probably not be able to benefit from any possible future developments in hair cell regeneration.
- An April 2007 study confirms that people with cochlear implants are more susceptible to bacterial meningitis and should be vaccinated against the disease.
- Because of the magnet embedded in their heads, recipients cannot undergo MRIs, a fairly common and very important medical diagnostic tool, without having the magnet surgically removed from under the skin of the skull.
- There is a slight danger that the surgery might damage the facial nerve.

Hybrid Cochlear Implants

As we mentioned above, the main objection people have to cochlear implants is the loss of residual hearing in the implanted ear. A large percentage of people with sensorineural hearing loss (so-called “nerve deafness”) have a severe loss in the higher frequencies - the common “ski slope” audiogram configuration. They also retain residual “normal” hearing in the low frequencies and are reluctant to sacrifice it. To address this large population, Med-El and Cochlear Corporation have created



Ski Slope Audiogram
Courtesy of: GN Resound

“hybrid implants,” both undergoing trials in this country, and Advanced Bionics is rumored to have one in the works as well. These devices capitalize on the fact that the hair cells in the cochlea respond sequentially to different frequencies, running from high frequencies at the beginning of the snail-shaped spiral to low frequencies at the end deep within the inner ear. By inserting a shorter electrode array only into the first section of the cochlea, the hair cells at the end of the cochlea that stimulate the auditory nerve when low frequencies enter the ear remain untouched, preserving their natural hearing.

What further improvements can we expect to see in coming years?

- Improved battery life. So far only Advanced Bionics offers a rechargeable battery with a relatively short life. This should improve.
- A totally implantable cochlear implant. Researchers will eventually solve the technological difficulties of implanting the entire device under the skin of the skull.
- Researchers at the University of Michigan are holding trials of “thin-film electrodes” (instead of the traditional bundle of wires) inserted with a pneumatic tool that allows easier and deeper insertion. Using this new technology, the number of frequencies stimulated can increase from the standard 16 or 22 to 128 electrodes.
- Another research team at the University of Michigan is investigating an auditory nerve implant that might supersede cochlear implants. It’s still 5-10 years in the future.
- The use of low-energy infrared light to stimulate the auditory nerve instead of electrical impulses. A study at Northwestern University is investigating this possibility, which might lead to the development of a “more precise implant that helps people who have profound hearing loss to distinguish speech in noisy environments.”

Auditory Brainstem Implants (ABIs)

As we mentioned earlier, people whose auditory nerves do not function are not candidates for cochlear implants. The auditory brainstem implant is particularly relevant for people with NF-2 (neurofibromatosis type 2, a hereditary condition in which acoustic tumors grow on the auditory nerve, which must be severed during life-saving surgery). Instead of using a fine electrode inserted into the cochlea, the ABI uses a flat plate implanted directly on the brainstem to bypass the auditory nerve. Results from this device are similar to those from the original single channel cochlear implant. They let the user hear environmental sounds and help with lipreading. Some users do even better. The House Ear Institute is conducting trials of a second generation device, the penetrating auditory brain implant (PABI), that uses needle-like electrodes as well as the electrode plate of the ABI. The combination improves the perception of pitch and appears to produce improved understanding of speech.

The Effect of Hearing "Gain" on Relationships

There is a joke about an old man who got hearing aids that improved his hearing tremendously. One day, he went to his doctor, who said conversationally, "Your family must be thrilled that you can hear so well now." "Oh," said the old man, "I haven't told them anything about it. So far, I've changed my will five times."

Usually, the change in your hearing with well-fitted hearing aids or a cochlear implant is very obvious, though it may be slow as you become accustomed to the devices. Just as hearing loss has a great effect on relationships, so does enhancing your hearing, particularly if you have had a significant hearing loss for a long time. You may be elated by the change, energized because you've conquered so much stress and fatigue. You may actually feel reborn in many ways. On the other hand, your spouse or significant other must become used to the "new you." In addition to your new energy and high spirits, you may feel more independent and assertive, ready to take a far more active role at home and work. Friends and family will have to unlearn some of the behaviors they've honed over the years to support you, and let you unfurl your wings. You'll have to micro-tune your relationships and have patience as those around you assimilate the changes. Even small adjustments can have an impact. If you've deferred to oth-

ers in the family to answer the phone or the doorbell, for example, you may have to develop new guidelines. If you're now able to understand speech competently without speechreading, you may be able to have discussions, romantic and otherwise, in the dark. Reversing accommodations may be almost as difficult and time-consuming as adopting them. The keyword again is patience.

6. ASSISTIVE TECHNOLOGY

Everyone knows about hearing aids (although they might not know much about them); however, few people know about other devices available for late-deafened and hard of hearing people. In this chapter, we'll introduce you to some gizmos, gadgets, and technology that you might want to explore more fully.

"While there is no question about the necessity of a hearing aid for most hearing-impaired people," writes Dr. Mark Ross, "often...a hearing aid is not enough." Many of us need additional assistive devices. In the next pages, we'll survey some of these.

We can break down hearing assistive technology (HAT) into several classes:

- **Assistive Listening Devices and Systems**
- **Alerting and Signaling Devices**
- **Telephones**
- **Mobile Telephones**
- **Alternate Methods of Communication**
- **Television Devices**

See the Appendix for references for each section.

■ Assistive Listening Devices (ALDs) and Systems (ALS)

In addition to hearing aids and cochlear implants, there are a number of assistive listening devices and systems on the market that amplify sound and may be of help to people who have some residual hearing. They can be very helpful in situations where hearing aids don't do the job well: noisy places (such as restaurants), large group meetings (churches, senior center presentations), classes, business meetings, etc.

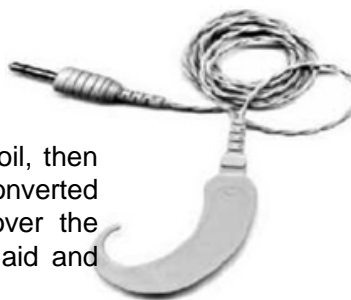
The objective of all of these listening devices is the same: to increase the intelligibility and clarity of speech by putting the microphone closer to the speaker's mouth or sound source, and by decreasing background noise. Audiologists speak of this as increasing the signal-to-noise ratio (SNR).

These devices generally consist of:

- an **external microphone** for the person who is speaking, OR a direct cable to the sound source (if other than a live speaker)
- a **transmitter**: used in larger systems
- a **receiver**

People with mild hearing losses can use headphones or earbuds with the receiver. People with severe and profound hearing losses often use a neckloop or silhouette that works with the hearing aid's telecoil (t-coil) (see Chapter 5).

A silhouette is a thin piece of hook-shaped material containing a small loop of wire. This loop generates a weak magnetic signal that can be picked up by the hearing aid's telecoil, then amplified by the hearing aid and converted into sound. The silhouette hooks over the ear and rests between the hearing aid and the side of the head. If you also wear glasses, the real estate behind your ear



Silhouette Adapter

may become fairly crowded. Another highly efficient way to connect to the listening device is to use a cable that goes to the direct audio input (DAI) jack or boot at the bottom of the hearing aid; this feeds the sound directly from the sound source or input to the hearing aid's amplifier.

Cochlear implant users can often use a cable or an audio adapter accessory that plugs directly into a sound source, such as one of the assistive devices listed below, a CD, cassette, or MP3 player, etc. It may take a bit of fiddling with plug adapters and you may need a program that shuts off the internal microphone.

There are several types of listening devices:

- **Hardwired Devices:** These contain an amplifier, battery and volume control, and either a built-in microphone or a jack for an external one; they are the size of a pack of cards. These are best used as personal amplifiers in one-on-one situations. For example, a hearing aid user might connect an external microphone directly to his hearing aid's DAI boot. These are limited in how much they can help in larger settings because the user is tethered to the microphone by a wire. Still, these devices have

several advantages. They work very well one on one, such as in a noisy restaurant, and they are relatively inexpensive.

- **FM Systems:** These broadcast sound over designated FM frequencies to individual receivers. For portable use, the transmitter and receiver can be battery-operated; each is approximately the size of a deck of cards. For large meetings, an AC-powered large area transmitter is often used. It connects to the existing public address sound system or mixer in a meeting room with multiple microphones in use. Anyone with an FM receiver that is tuned to the appropriate frequency can listen to the sound source through headphones, a neck-loop, silhouettes placed between the head and BTE hearing aids, cochlear implant patch cord, or DAI. The receiver can be placed in a pocket or hung around the neck. Some new hearing aids even have built-in FM receivers. The systems are highly portable and can be very effective. On the down side, they tend to pick up interference from other broadcasts on similar frequencies. They are also not suitable for highly confidential proceedings as anyone with a scanner can theoretically “listen in” on what is being said.

- **Infrared (IR) Systems:**

These look very similar to the FM devices, but transmit sound using infrared light waves from a public address system or microphone through an infrared light emitter to the receiver. Infrared systems are favored for use in theaters. Although they don't have problems with interference, as do FM systems, they cannot be used outdoors in bright sunlight, and the receiver must have an unobstructed “view” of the transmitter. They, too, can be used with neckloops, direct audio input, and other listening attachments. IR systems are by nature suited to confidentiality since they cannot be “intercepted.”



Infrared (IR) Receiver

- **Audio Induction Loop Systems:** These are permanent or temporary installations in a room and are popular for small group

meetings because they are portable and relatively inexpensive. A wire runs around the periphery of the room and attaches to an amplifier into which the microphone is also plugged. The amplifier converts the sound into electrical signals and feeds them through the wire, creating a magnetic field within the loop. Listeners inside the loop can pick up the sound using the telecoils of their hearing aids or cochlear implants, or via a small Audio Induction Loop Receiver and listening attachment. Sound quality varies widely; there may be interference from fluorescent lighting, and there can be dead spots in the magnetic field. Loops can be assembled inexpensively from parts from an electronics store. I know several people who have loops in their homes, around their televisions or stereos, and even in their cars. The neckloop is a personal version of this.

For meetings, systems featuring individual microphones positioned around the table feeding into a mixer, and, from there, into an FM transmitter, work particularly well. Or you can pass the cordless microphone around the table, which is a distant second best (although it



Oval Window
Audio Loop

does help remind speakers to take turns talking and only when in possession of the microphone). A personal FM system can also work quite well in a classroom or lecture type situation, where the microphone can be taped to the lectern, plugged into the PA system's audio output jack, or the speaker can put the transmitter in a pocket and use a lapel microphone.

Many churches, synagogues, hotels and public places may have ALDs on hand, though they may not have the type of receiver and listening attachment that you prefer. You may have to bring your own neckloop or patchcord. A single FM transmitter at the podium or connected to the existing public address system can transmit to multiple receivers. Other facilities, particularly movie theaters and concert halls, prefer Infrared Systems. Some of these use headphones; some use a stethoscope-type receiver that hangs under the chin. Different FM systems transmit on different frequencies and not all FM receivers are multi-channel or field-tunable, but most infrared receivers will

work with any infrared emitter. If you purchase one of your own for home use, you can also take it with you to the theater. When purchasing any ALD, make sure that you arrange for a trial period.

Another approach, used mainly in the classroom, but also of use in meeting rooms, is the sound-field system. Mark Ross describes these as “basically Public Address (PA) systems with the inclusion of a wireless microphone.” The teacher speaks into the microphone. The sound is transmitted to a receiver/amplifier connected to a loudspeaker located in the ceiling, the corners of the room, on walls around the room, etc. The result is that the voice is amplified about 8-10 dB (as opposed to an unamplified 6 dB) above background sound, thus increasing the speech to noise ratio. This takes some of the strain out of hearing what is said in the room. The systems are either FM or infrared based. The advantage of the latter is that it won’t interfere with similar systems in the same building and won’t pick up interference from stray FM systems in the neighborhood. These systems seem most suited for users with mild hearing loss. For more severe losses, FM systems are still recommended.

■ Alerting Devices and Signaling Systems (ADSS)

In an issue of the now defunct magazine *Life After Deafness*, publisher Gayle McCullough tells how her husband locked himself out late one night and spent hours in the cold trying to get her attention. All of us have tales of this sort to tell, some funny (at least in retrospect), some sad, some tragic. Luckily, simple solutions - audible, visual, and tactile -- are available in the electronics department, as well as not-so-simple solutions in the four-footed, wet nose department (see the next section).



Vibralite
Vibrating Wrist Watch

Deaf people have used signaling devices for years: lights that flash when the doorbell or phone rings or a baby cries; vibrating alarm clocks and “bed-shakers” to wake the sleeping, specialized fire alarm and carbon monoxide detectors that flash strobe lights and, in some cases, can trigger bed shakers as well.

Some of these systems are quite simple; for example, you can buy an inexpensive module that plugs into the wall at one end and into a telephone jack and a lamp at the other. When the phone rings, the light

flashes. Or you can purchase a single unit that flashes different sequences depending on the source of the sound (doorbell, telephone, crying baby, for example). There are Dick Tracy-style watches that vibrate when a transmitter “hears” a sound, and pagers that vibrate and show a code when an environmental alert is triggered. If you have some residual hearing, you may want to try out adjustable audible ringers with your telephones. There are alerting devices just for one specific need, and signaling systems which enable you to add components and expand functionality as needed to outfit your entire home.

As we mentioned before, there are also special smoke alarms with very loud horns and flashing strobes, as well as vibrators that fit either under a pillow or mattress. Kidde has brought a wireless smoke alarm to the market that can activate other wireless alarms in different rooms. But according to a study from Gallaudet University cited by Robert MacPherson, owner of the bhNEWS listserv (see Chapter 2), the only smoke alarm that will awaken sleeping deaf people 100% of the time is one that uses an intermittent bed-shaker. A continuous bed-shaker awoke 91% of the subjects, and a strobe awoke only 33%.

Homegrown devices can be quite complex and clever, too. For example, Jonathan O'Dell, profiled in Chapter 1, invented a Rube Goldberg-type wake-up alarm as a young boy. He used his Walt Disney bell-type alarm clock with wind-up key, Lego parts, and a small container of water. “The container of



Smoke Alarm with
Bed Shaker

water was held over my pillow in an upright position by a thread which held back the tripping force of a stretched rubber band. When the alarm clock went off, the wind-up key on the back of the clock rotated, pulling another thread that was attached to a Lego motor control switch. This, when tripped, made an axle turn rapidly. I had fastened a razor blade to an extension of this axle, so that when the alarm went off, the arm swung, cutting the thread, letting the rubber band spill the water on the pillow (and presumably, my head, had my mother allowed me to actually use the contraption).” It appears that she was impressed by her son’s ingenuity but less so by the razor blade/wet pillow combination.

Hearing (or Signal) Dogs

Not all assistive devices are inanimate. Every morning, Creature, a shaggy little dog of uncertain ancestry, jumps into bed to wake my deaf friend Barbara at the ringing of the alarm. As they drive to work, Creature, now formally dressed with her orange leash, alerts Barbara to the sirens of any approaching emergency vehicles. Creature has become a fixture at the large high tech company where Barbara works as a technical writer. After greeting the security guard, she makes herself comfortable on her bed under Barbara's desk. The dog responds to ringing telephones and also alerts Barbara when someone comes into her cubicle or calls her name. At home, Barbara feels more secure knowing that Creature will let her know if someone rings her doorbell or knocks on the door. Creature has also been trained to lead Barbara to the sound if the phone rings, the kettle whistles, or the smoke alarm sounds.

Creature is a graduate of the hearing dog training program at a humane society on the west coast, where Barbara used to live. There are many other programs that train assistance dogs, as well as private trainers. If you're an experienced dog trainer, you may be able to train your own dog to respond to a number of signals, but it takes a great deal of work, time, and effort. I tried to get my own dog to alert me to a ringing telephone, but she's from the classic Alfred E. Neuman "What, Me Worry?" school of thought. She does, however, tell me when someone is at the door, as do most dogs and some cats that I know, with or without training. And, although she sleeps happily through fireworks and thunderstorms, on the two occasions when the low battery warning on my smoke alarm was beeping, she kept me awake all night wondering why a terrified 60-lb. dog was trying to sit on top of my head. Hearing (or signal) dogs, much like seeing-eye dogs, are by law permitted to accompany their owners into places of public accommodation.



Hearing ear Dog

Telephones

For late-deafened people, telephones are the ultimate nemesis. In our hearing pasts, they played a very large role, something to which we hardly gave a thought. Now, they've become instruments of torture.

We can't hear them ring; we can't hear telephone conversations. When we raise a receiver to our ear, our hearing aid may buzz from interference or we may experience a loud whistling, if the sound from the aid is reflected by the phone back into the hearing aid microphone (feedback). Yet, we live in a world that is increasingly turning to cellular phones and voicemail. Luckily, we can address this situation from a number of angles.

Hearing Aid (Telecoil) Compatibility of Telephones

As of 1988, all corded phones sold in this country must be "hearing aid compatible" (HAC), able to work with a hearing aid telecoil. (For more information about telecoils, see Chapter 5.) Using a strong telecoil eliminates background noise and effectively lets you amplify the speaker's voice exclusively. What it doesn't do is let you lipread. For that, you'll need a videophone, which we'll discuss later in this chapter.

Amplified Telephones

If your telecoil isn't strong enough or your hearing aid doesn't have one, you can purchase an amplified telephone. Ten years ago, these hardly existed and this section instead discussed handset amplifiers. The latter are still available, but rare. Most are portable, and some models strap onto the handset of any telephone, cellular or otherwise. Some are small boxes that can be connected between the handset and the telephone base. Some are replacement handsets with volume controls, but there are often electronic compatibility problems between amplifiers and telephones, so you'll have to test them. They have been largely supplanted by amplified telephones, corded and cordless, which can increase the volume with a simple slide switch or knob. A look in the catalog of Harris Communications (www.harriscomm.com), one of the largest suppliers of assistive devices, finds 48 different models, and that doesn't include speaker-phones, which are another possibility for many people. Amplification can vary, so it's best to test drive one of these before buying.



Ameriphone Amplified telephone

TTY (Text Telephone)

Those of us who can't hear on the telephone use a TTY, an acronym for teletypewriter. A TTY is a small, table-top unit with a keyboard, a one-line screen for visual display of text, and an acoustic coupler, into which you place the telephone handset. (On some models, you can use "direct connect" and plug your telephone line directly into the TTY). Some TTYs have small, built-in printers. Many have an auto-answer mode that works like an answering machine and can save and print messages from another TTY user if you don't answer the call yourself. TTYs are sometimes called TDDs (Telecommunications Devices for the Deaf). More recently, the federal government tried unsuccessfully to popularize the acronym TT for (text telephone). Whatever you call them, they were invented in the 1960s by physicist Robert Weitbrecht, using a converted newsroom teletypewriter machine, an enormous contraption.



Ultratec 4425 Printing TTY

Two TTY users can type messages to each other over the phone lines. If it sounds a lot like computer "chat," it is. Because even champion typists type much more slowly than we speak, TTY conversations are very slow, so we use many abbreviations. But you don't have to be a whiz-bang typist to use a TTY. Typing with one finger works just fine with some practice. Most telephone companies give a discount to TTY users, since calls take longer. As we'll see in the next chapter, the TTY user can also voice his or her part of a conversation using the Relay Service with Voice Carry Over (VCO). If that's the way you use the relay, you can buy a special phone known as a VCO phone that lets you connect to the relay service and see what the other person says on a small screen. We'll have more to say about these in Chapter 7.

One of the main shortcomings of using a TTY is that both parties must have them or use the Telephone Relay Service. (See Chapter 7). Can you use your computer to communicate with a TTY? Yes and no. TTYs "speak" in "baudot" while computers use "ASCII" code. Unless the TTY has an ASCII option (most new ones do), you can't communicate directly with a standard computer modem, and dual-purpose modems are relatively slow and quite expensive. Even

if the TTY can communicate in ASCII, your modem may not be able to slow down to the speed at which the ASCII TTY operates. A more flexible method for chatting is to use an instant messenger program, such as AIM® on AOL. We'll discuss this later in this chapter ("Alternate Methods of Communication").

TTYs are "old" technology. Nevertheless, they're useful for communicating with other TTY-users who don't use computers. If you have difficulty handling voice calls, they can be far less stressful for making business and other important calls. Some TTYs have small built-in printers that can record a conversation on rolls of adding machine paper. This can be a nifty feature if you need a record of a call.

Some TTY Terms

GA	Go Ahead (It's your turn)
SK	Stop Keying (Goodbye)
HD	Hold
TMW	Tomorrow
MTG	Meeting
PLS	Please
Q	Used instead of a question mark to indicate question
U	You
UR	Your
CUZ	Because
MSG	Message

If you speak with someone frequently, you tend to invent your own private set of abbreviations.

Videophones

One of the most popular exhibits at the 1964 World's Fair was the Picturephone at the Bell Telephone System pavilion. Consisting of a telephone handset and a small, oval television, visitors could both see and hear when they phoned someone in a neighboring booth. Fair-goers could also make calls to special booths in New York, Washington and Chicago. Rates for a 3-minute call ranged from

\$16-27 (an average of about \$120 in 2004 dollars). The concept wasn't even new at that time. Bell had demonstrated a one-way picture phone in 1927. The user was Herbert Hoover, who would soon be elected president.

AT&T actually launched residential picturephone service in 1970 in Pittsburgh and Chicago. Customers paid around \$160/mo. to rent the equipment and get a whopping 30 minutes of calling time. The service was discontinued in 2004; fewer than 500 people had subscribed to it. A victim of the times, the



Ojo Videophone



Sorenson VP200



D-Link Broadband Videophone

service was too expensive and the photo quality was fuzzy.

Technology has finally caught up with the concept. With the arrival of high-speed Internet connections and inexpensive webcams, we now have the necessities for useable videophones that provide both audio and visual output. Deaf people who sign have embraced them, to the extent that some have given up their traditional "land-line phones" altogether, and mothballed their TTYs. This is a dangerous situation considering that TTYs can operate on batteries during emergency power outages, while videophones will be useless and are not able to call 911 directly for location identification.

The hard of hearing and late-deafened populations who don't use sign language but do have some residual hearing have been slow to adopt the systems, even though they can be useful for speechreading. Current users of videophones include large corporations who use them for teleconferencing, and computer owners, who use inexpensive webcams and Internet messaging software. Two people who sign can also use videophones to communicate directly with one another at no additional cost beyond the monthly fees associated with broadband Internet service.

Massachusetts Telephone Equipment Distribution Program (MassEDP)

Massachusetts residents who are deaf or hard of hearing can qualify for a program administered by Verizon (and developed by MCDHH, the Massachusetts Commission for the Blind, the Massachusetts Rehabilitation Commission, the Department of Public Utilities, and representatives from the user community) that distributes special telephone equipment to people with disabilities at no charge (if your income is over \$50,000, there is a small charge). MassEDP includes amplified phones, TTYs and VCO phones among its products. A late-deafened, deaf, or hard of hearing person may choose either an amplified telephone or a TTY (see below) and two signaling devices, or an amplifier and two signalers. To receive equipment, you must be certified by a medical specialist and send this verification to MCDHH.

For more information and an application, call:

- **Verizon**
280 Locke Drive, 4th Floor
Marlboro, MA 01752
800/300-5658 (v/tty)
www.massedp.com
- **MCDHH**
617/740-1600(voice)
617/740-1700 (tty)

Mobile Telephones

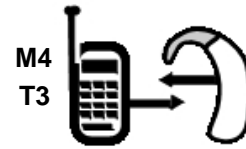
The wave of the future is wireless communication. Advocacy by HLAA and other hearing loss organizations has gone a long way toward making these accessible to people with hearing loss.

Cell Phones

In 2003, the exemption for wireless phone hearing aid compatibility was removed, and a timetable for compliance was established. The Federal Communications Commission (FCC) has developed two rating system for emissions, the M (microphone) and T (telecoil) ratings. The ratings range from 1 (poor) to 4 (excellent). If you use a cell phone with the M (microphone) setting on your aids, look for a

high M rating for a cell phone. If you use your T or MT (telecoil and microphone/telecoil) settings, look for a high T rating. All cell phones with T3 or T4 ratings also have high M ratings. An icon on the box indicates the level of compatibility.

Unfortunately, the wireless industry has been lax in labeling phones as hearing aid compatible and the FCC hasn't enforced the regulation. In a landmark agreement in 2007, the Hearing Loss Association of America and a number of other hearing loss advocacy groups forged a mutually beneficial agreement with the industry, the first time such an agreement has been made without federal oversight. We should soon be seeing more compliance in labeling and selecting a cell phone should be far easier, at least as far as the technical specifications go.



As Neil Bauman, Ph.D. writes, other factors such as phone back-lighting and display may also cause interference not measured by the ratings. (This is called baseband magnetic interference.) He notes, too, that if the store where you try out the cell phone is near a cell tower, the phone will put out less power for reception, but interference may be greater if you move away from the tower and the phone has to use more power. This is one reason that it is important to make sure you receive a trial period when purchasing a cell phone.

Some hearing aid manufacturers have voluntarily adopted the same sort of rating system for immunity to interference from electromagnetic and radio frequency "noise." The lower the number, the better the immunity; M2 and T2 are the best ratings for hearing aids.

In general, clamshell (flip) phones work better with hearing aids when the microphone and earpiece parts are separated. Different service providers use different technologies. Most people find that CDMA, used by Verizon and Sprint PCS, produces less interference.

Qwerty-based Cell Phones or Smartphones

Developed In the early 1990's, these multifunction phones have been embraced by the Deaf Community. They combine the features of a cell phone with a "Qwerty" keyboard, a small version of a computer keyboard. You can find a smartphone that includes the software applications of a PDA (personal digital assistant, a handheld personal computer such as the Palm Pilot), with its PIM (personal

Information management) software that includes calendar, address book, and other functions. You can text message using a tap-style numeric keypad on most cell phones, but if you want to send more than an occasional short message, you'll want a qwerty-based smartphone. Smartphones let you receive and send email, load other applications, connect to your desktop or notebook computer, play games, and use messaging software. Some also include cameras and play music and videos. Whether it's a cell phone with a PDA or a PDA with a cell phone is moot. Its most important function for people with hearing loss is communication. You can text message using IM for realtime chat, email, or SMS (short message service, which we'll discuss in the next chapter). You can usually sign up with a provider for Voice only, Data only, or Voice and Data plans, depending on how you intend to use the device. The popularity of text messaging has grown to the point where the medical profession recognizes an old malady under a new name, "Blackberry thumb." Previously known as "Nintendo thumb," it manifests itself in tendonitis or aggravated arthritis from typing on a tiny keyboard using the thumb.

Among the most popular smartphone variants are the Sidekick, Blackberry, LG Electronics (LG),

Samsung, Motorola, Nokia, High Tech Computer Corp (HTC) and Palm/One Treos. The market is

changing rapidly as manufacturers race to include more features. This year's hot trend appears to be video calling via a video camera facing the user, with a high speed connection. This paves the way for mobile video relay service and realtime video chatting.



Sidekick LX



Blackberry

Telephone Headsets

You may also use a headset with many telephones. Some of these have volume controls. Some have a microphone that eliminates background noise. They work best for the unaided ear or with aids where the receiver is deep within the ear, such as ITC and CIC aids, or open fit aids; putting a headset over a BTE aid will probably result in feedback (whistling). For people who want to use their telecoil settings with phones, either cell phones or amplified phones (regular

phones do not have the necessary 2.5 mm plugs), you can choose from a wide array of headsets, amplified and not. Most make use of “silhouettes” that fit between your head and a BTE aid. If you’re attempting to hear calls through both ears, the “dual” models of these may be the best way to go. Among the most well-known of these is the HATIS (Hearing Aid Telephone Interconnect System). If you prefer neckloops, try the Clear Sound CLA7 UltraClear



HATIS Headset

Power Neckloop™. This is amplified and requires batteries.

Because telecoil placement and power varies so much from one aid to another, you’ll have to try out these headsets and neckloops before buying. Once you find



Clearsound Neck Loop

one that works for you, you’ll quickly realize that it’s fine for outgoing calls, but awkward for incoming ones, unless you’re on the phone all day and remain “plugged in.” If you just use it to receive occasional calls, by the time you put on the headset or loop and plug it into your phone, the caller has long since hung up. One solution appears to be the emergence of the first generation of hearing aids with built-in Bluetooth, which we’ll discuss later.

If you use a cochlear implant, you may or may not have a telecoil. Mine (an Advanced Bionics Auria) doesn’t, but it does come with a direct connect attachment that I can plug directly into a cell phone or amplified phone. So far, I haven’t bothered since it involves changing earpieces. I’ve had pretty good luck just using the Auria’s T-mic, which I wear all the time; it puts the microphone in my outer ear, directly in front of my ear canal.

Bluetooth

Named after a 10th century king of Denmark, Harald Bluetooth, this is a wireless technology that has recently made a big splash in the high-tech world. Using unlicensed radio frequencies, Bluetooth can connect as many as seven devices to a master device at very short range, usually up to about 30 feet. At this writing, a few new hearing aids from Oticon and Starkey have built-in Bluetooth



Bluetooth Headset

receivers. ELI makes a Bluetooth DAI boot and neckloop that converts any hearing aid to Bluetooth. Paired with a cell phone that is Bluetooth enabled, you can dispense with the wires of silhouettes and other corded telephone interfaces. In the future, other audio devices such as stereos will undoubtedly also have Bluetooth technology.

Alternate Methods of Communication

Calls involving TTYs take at least four times longer than regular voice calls. For this reason, many late-deafened people encourage their callers to use other methods of communication when messages don't demand immediate attention or a lot of back and forth discussion. Although only TTY, Relay calls (see next chapter), messenger programs or computer chat are "realtime" and provide the give and take of live conversation, many communications lend themselves to simpler forms that can be read and answered at our convenience.

Internet Chatting

Relatively few people in the hearing world have TTYs. One solution to this dilemma, assuming that both of you have computers with Internet access, is to use them for realtime chatting. Modem to modem chatting is very similar to TTY chatting. You and the caller take turns typing messages to each other; the text displays on your monitor. After making an appointment to chat, both users turn on their computers and start AOL's Instant Messenger (AIM), Yahoo's IM, or a similar program. Once you learn how to use the software, chatting is a breeze. One person types at a time, then the other answers. The keyboard is larger and better and the screen is obviously on a completely different level than the small one-line display of a TTY. You don't need expensive computer equipment to chat. Obviously, faster is better, but the slowest, most antiquated personal computer with a dialup connection to the Internet will do the trick. Modem to modem chatting isn't limited by computer or modem speed; it's limited by typing speed. If you want to communicate with a friend or relative who can't afford a TTY, it may be possible to outfit the other person with an old PC. You'll not only be able to chat, you'll also be able to send files back and forth, but that's another story.

IM isn't limited to two people. You can chat with any number of people at the same time, and you can open a "chat room" and invite

the world. Because everyone is typing madly, but only one message can be displayed on the screen at a time, conversations among multiple users can become decidedly fragmentary.

When you are using your computer, anyone who is online and uses the same messaging software can reach you, unless you post the equivalent of a "Do not disturb" sign on your computer door. Although AIM (AOL Instant Messenger) is the most popular, MSN, Yahoo!, Google and others all have their own proprietary messaging software. Mobile applications of these programs are also available for your notebook computer.

New Kids on the Block

Nevertheless, the problem still remains of how people who use their voices can communicate with people who sign and vice versa. In addition to the relay services we discuss in the next chapter, there are a number of newer devices that can facilitate communication.

Ubi Duo

Invented by a deaf man and his father, the Ubi Duo (pronounced you-bee) is a battery-powered stand-alone device that lets up to four people chat with each other. Each person uses a screen with keyboard and types to the other. The machines can connect to a computer with a USB cable, have adjustable font size, built-in emoticons, memory and 40 different commands and options to customize your conversations. The devices have a wireless range of 500 feet and hinge together into a 6 lb. package. The Ubi4Tel enables 2-way conversation over a telephone line when calling another Ubi Duo. Up to four people can participate in a conference call. The basic 2-unit system costs around \$2000.

MedBio "Speak 'n Read (SNR)

MedBio bills this as "the world's first and only voice recognition system." It consists of a handheld computer with MedBio's ApStack software. When a person speaks, the software converts what is said into text that is displayed on the monitor of the computer. The deaf user can then respond by talking or typing. The system, in its latest incarnation, costs approximately \$3000.

Signtel

Signtel is another product that uses speech recognition, this time to translate speech and text into sign language. It is sold both as a

software product or as software installed on a notebook computer. The software recognizes 30,000 words, including 1000 idioms.

Fax

When I bought my first fax machine, I had no idea what I'd do with it. Now, I can't imagine what I'd do without it. When I walk in the door, the first things I check are my TTY and my fax machine to see if anyone has left a message for me. Many of the people I do business with have fax machines, and prefer to receive faxes from me rather than relayed calls. I have not spent much time practicing making voice calls with my cochlear implant, and still feel insecure about using it for business calls, although I often do quite well with it on the phone.

Most new computers come with internal modems for dialup Internet service, or wireless cards for broadband Internet service, if you purchase a notebook computer. They're excellent for faxing files you've prepared on your computer, if your word processing program supports faxing or if you subscribe to a service such as eFax, which sends and receives faxes for you and can forward them to your hand-

held device, if you have one. But they're less ideal for receiving faxes. The computer must be turned on to receive a fax and you'll need a separate scanner if you want to send photos or graphics, even a fancy letterhead. Good stand-alone fax machines are fairly inexpensive; prices of machines that use regular paper have now fallen below \$50, and a number of manufacturers sell multi-function machines, both laser and inkjet, black or color, for the home office; they serve as fax machines, computer printers, scanners, copiers, and sometimes, voice telephones. The prices are reasonable and many aren't larger than a standalone printer.

Email

For those of us with computers, electronic mail (email) has become a way of life. I can leave a message for someone at midnight and have my reply as soon as the recipient checks her email in the morning. Or I can post a question on an email discussion group and may have my answer within moments if others are logged on. Many of my editors prefer that I send stories by email, and I find that I'm doing more and more of my rental business this way. For me, the advantages are many. I can compose messages and pick up mail during a spare minute or a break. I need not worry about interrupting someone at work or paying long distance rates. I can keep a record of all correspondence and don't need an intermediary such as a Relay operator

to help me with a call. Nor do I have to find an envelope and stamp or drop off my letter in a mailbox. All I do is hit the Send button. And I can send copies to all my friends if I'm so inclined.

To start using email, you'll need a computer, modem, and an Internet Service Provider (ISP) or online service such as AOL or Earthlink. These are pretty much standard issue on any new computer you might buy, along with a built-in wireless card if you purchase a notebook computer. The latter will let you take your computer to any WiFi hotspot - a Starbuck's, for example - and connect to the Internet. If you live in a rural area, as I do, without highspeed Internet service such as cable or DSL, you may have to use slow dialup service or you might get lucky and discover that there is a wireless provider in the area, a solution used more and more in otherwise hard-to-serve areas.

When you sign up with a provider, you'll receive a temporary password, with directions for setting up your web browser and email program. In fact, if you have a computer, you've probably already received several pounds of AOL or Earthlink software in the mail or tucked into computer magazines. The services charge a monthly rate for a given number of hours of usage, or a tiered flat rate fee with unlimited hours. In addition to email, you'll be able to join listservs, such as the ones we discussed in Chapter 2, get weather reports, surf the Internet, receive stock quotes, and access many other options. New users and teenagers often get carried away by Chat Rooms, where they can "talk" online to others with similar interests and problems. Experienced users know that nothing runs through usage time as quickly as chatting, which is, of course, why the online services promote it.

There are thousands of small Internet Service Providers (ISPs) across the country. Many of these services offer an email address and unlimited time each month for exchanging messages and visiting websites. Like the online services, your monthly fee also includes free storage for a Web page, if you'd like to create one. If you want speed, you can sign up for "broadband": DSL, wireless, or cable Internet service. If you wish to surf the web or send photo and graphics files, which are quite large, you'll need the additional speed of broadband. You'll also need it if you use an Internet phone service, which we'll describe in the next chapter. As noted before, in some rural areas, WiFi is the only broadband available. When shopping for an ISP, look at more than price:

- Check to make sure that the service has local access numbers in your area so that you don't have to make a long distance call to log on.
- Try to find out how responsive Tech Support is.
- See if the service offers a trial membership so you can test it.
- Ask if free software is included with your membership and if there is an initial setup charge.

■ Televisions

For some reason, many of us find it very difficult to speechread television. That might be understandable for dramatic programs, where the camera angle is rarely full-face, but there aren't even many television news reporters whom I seem able to speechread with ease. Fortunately, there are a number of solutions to this problem on the market.

Infrared Systems

Inexpensive systems, similar to the ones we discussed earlier in the section on IR personal listening devices and systems are a popular choice for use with televisions. You've probably seen them for sale in department and electronics stores. They come with a unit that connects to the TV and sits on top of it, and a rather heavy headset that the user wears. Ads herald them as "marriage savers": "now, your spouse can sleep while you watch the Late, Late, Late Show." If one of these works for you, fine. Don't give up the search, though, if it doesn't. A more powerful, but expensive, unit may fit the bill. And remember: you can use an infrared receiver with any infrared transmitter, including the ones used by many movie theaters and concert halls.



Infrared TV Listening System

In addition to infrared systems, you can also create an audio loop around your television. See the beginning of the chapter for information about these.

DTV Day Is Coming

On February 17, 2009, all U.S. television stations will shift from analog to digital programming. Digital television provides improved pic-

ture quality and sound. To receive reception after that date, you must either purchase a digital television or an OTA ("over the air," which means using an antenna) converter box. Analog televisions that receive their signals through cable or satellite service will not be affected. At this writing, the boxes do not seem to have arrived yet in stores. To help analog television owners afford the cost of the converter boxes, the federal government has developed a coupon program for converter boxes. Each household with an analog tv set is entitled to two \$40 coupons from January 1, 2008 to March 31, 2009. The coupons cannot be combined.

Currently, those who have dared to be at the forefront of this change and have gone out to splurge on a HDTV set have found, to their amazement, that their captions are now coming from the digital cable box, something most cable installers will not tell you when they are installing the box for you. Unless you set up the cable box correctly, you may not receive captions.

There are also problems with DVD recorders using the HDMI interface, which does not incorporate caption transmission, meaning that the show you just recorded will play beautifully -- but completely without captions.

In Closing

Finding the best assistive devices and technology is a complicated business and it changes on a nearly daily basis. It's best to gather as much information as you can and try before buying. Check out mail order catalogs to see what's available. Conferences and conventions often have displays by vendors and companies. Always carry a copy of your audiogram when you go shopping for assistive technology. Some audiologists carry devices, but the profit margins on these are low, and they rarely stock a wide selection. There are several stores in the state whose owners have a great deal of experience and expertise fitting clients (see Chapter 10 and the MCDHH website for a vendor list). The MCDHH CATTs department gives excellent group presentations and their staff is extremely knowledgeable. MassEDP can help you select telephone devices. Other people with hearing loss are a good starting point for acquainting yourself with what is on the market. HLAA and ALDA members can tell you what works for them. Remember that what works for others may not work for you, but that there are many alternatives.

In the next chapter, we'll take a look at some auxiliary services that can also make life easier.

7. AUXILIARY SERVICES

There are, in addition, a number of auxiliary services that can help in many of the communication situations that arise in business, school, and everyday life. Unlike assistive listening devices and systems, which are essentially useless for people with no residual hearing, these services are equally accessible to all late-deafened and hard of hearing folk.

Optional Telephone Services

In the last few years, Verizon has added a number of optional services that can be useful to late-deafened people (go to **Verizon.com**, select **Residential**, then **Online Support, Phone Service**, and **Calling Features**). More services are being developed all the time, as your local phone company thinks of new and innovative ways to part you from your money.

Distinctive Ring Service

Distinctive ring service, sometimes known as Ringmate, eliminates the need to have separate phone lines for fax, TTY, and voice phones. It's perfect for people and small businesses that don't have heavy traffic on these devices since it lets you have several different numbers on a single phone line, each with its own ringing pattern. For example, I have two distinctive ring numbers (plus my main number). The main number is my voice number. When someone calls it, my signaling light flashes a series of single long rings; if I don't answer the phone, these calls go to my voice answering machine. My second number is a fax number, which the signaler indicates by a series of two short rings. My third number is a TTY number, which the signaler indicates by a series of short-long-short flashes. That's all distinctive ring does by itself, used with a signaling light. I've heard of people who find this sufficient and manually switch on the appropriate device when the signal flashes. In order to route the call to the proper device automatically, however, you'll need a special unit. Newer fax machines often come with a built-in switch, but it usually only handles two different numbers, not three. Otherwise, you'll have to buy a switcher separately. For me, this has been an excellent investment since I don't have to be home to receive messages on the TTY, or faxes. And my answering machine can also take a voice message. You may be able to find a switcher at an office supply store, but they're becoming less common and fairly expensive. You'll find a good selection of them online. Once

you've got a model number, you may be able to find a used one on eBay, the online auction website (ebay.com).

Caller ID (CID)

Another product, Caller ID, uses a small box connected to the telephone line (or a telephone that supports Caller ID) to display the number and the name of the caller as soon as the phone has rung once. When I first tried this several years ago at my summer place in Vermont, I gave up in despair after a few weeks. Except for local calls, almost every call displayed an "Out of Area" or "Unknown" message. When I moved a few years later, I ordered the service and have been pleasantly surprised by its improvement. It's made the task of returning calls much easier, since I now usually don't have to go through an involved rigmarole to hear the caller's number (I'll have more to say about this in Chapter 9) or get someone to transcribe a voice message from my answering machine to get the number.

Call Answering Service

This service replaces your voice answering machine by creating one or more voice mailboxes for you. For people like myself who live alone without full-time answering machine transcription service (otherwise known as a hearing spouse or partner), it's a great convenience, since you can ask the Relay operator or Video Relay Interpreter to call your mailbox and retrieve your messages.

■ The Telecommunications Relay Service (TRS)

Voice telephones and TTYs speak different "languages." Using the Telecommunications Relay Service, a TTY-user can communicate with people who use voice telephones, and voice callers can communicate with a TTY-user. A TRS operator "relays" the call, acting as an intermediary. I make very few TTY to TTY calls because few of my friends own the devices. But I use my TTY many times each day to make Relay calls.

Since 2001, all states have been required to make their Relay Service Providers accessible by dialing 711. They may also have specialized 800 numbers as well. In a "traditional" relay call, I dial the relay, connect with a relay operator, and type to this operator the number I wish to reach. The operator then opens a second voice line to call the person with whom I want to talk. When the person on the other end answers, the operator announces that this is a relay

call and gives instructions, if necessary. During the conversation, I type, the relay operator voices what I type to the other person, and types the other person's spoken responses back to me so I can read them on my TTY screen.

However, since I grew up using a voice phone, this method seems very tedious and slow to me. My "profile," which can be filed by calling Relay Customer Service (see below) or at www.massrelay.com, indicates that I want to use Voice Carry Over (VCO), and this pops up on the operator's screen at the relay center in Holyoke, MA when I dial in. Using VCO, I speak directly to the caller, who then speaks to the operator, who types what has been said to me.

For people whose only use for a TTY is to make VCO calls, a number of manufacturers manufacture phones that resemble standard desktop amplified phones but include a small LCD screens. The user dials the relay, then reads what the operator types on the screen. There is no keyboard, just a standard numeric keypad. Krown also manufactures a portable version that can be strapped to any telephone receiver, even a cell phone.

I still need more practice to improve my telephone skills with my cochlear implant, and I rarely use the voice phone for important business calls. Using the Relay is slow, but it's the only way I can confidently call someone who uses a voice telephone. I have other means of communication,

but none where I can get an instant response or answer questions myself directly over the telephone. Unless one of my hearing employees or friends is available, I use the Relay for most of my telephone calls,



Krown Pocket VCO

7 even ordering pizza (employees at some establishments and businesses often speak with a foreign accent I find difficult to understand). People sometimes hang up because they're unfamiliar with Relay and think the call is a solicitation, but on the whole, most of the people I call are intrigued by it and cooperate fully. Relay operators are trained to type whatever they hear over the line and are obligated to adhere to a strict code of confidentiality. Someday, speech recognition software might automatically transcribe the voice part of the conversation. The standing joke for the last 20

years (at least) is that truly functional, full-featured voice recognition is always 10 years in the future. CapTel, described below, is the closest we have yet come to that ideal.

Two-line VCO Relay (2LVCO)

For those of us who have used voice phones in the past, traditional VCO Relay is a poor approximation of the real thing. In addition, many people aren't eager for the person they call to know that they're using Relay, which is unavoidable with the Relay calls we've described. Some people who are fortunate enough to have two telephone lines (not distinctive ring numbers, which are on the same line) and able to afford their care and upkeep, prefer a variation known as 2-line VCO (2LVCO). To use it, one line must have conference (sometimes known as "3-way") capability. When you dial the Relay on your TTY, you announce that you are making a 2-line VCO call and ask the operator to phone you back on your voice line. Answer your voice line with your voice and put the operator on hold while you create a conference call. You then dial the number you wish to call on your voice phone. There is no Relay announcement, so the other party cannot tell that it is a relay call. The operator types the voice user's conversation and it appears on your TTY screen, just like a regular relay call. For your part, there is no need to say "GA" or "Go ahead" and also unlike single line relay, you can interrupt while the other person is speaking. To receive a call, you go through a variation of this procedure. The operator remains invisible to the voice user and the call goes more quickly than a traditional Relay call. Because of this, it is useful to be able to use Turbo code if your TTY supports it.

Few people use 2LVCO because of the expense of installing a second line. To the best of my knowledge, only Wisconsin provides free installation and payment for a second line for people who use 2LVCO or 2-line CapTel, which we'll discuss below.

Relay Numbers

Mass Relay 711 (answered first by voice, then TTY)

800/439-2370 (tty/ascii)

800/439-0183 (v)

www.massrelay.org

Customer Service 800/720-3480 (tty/ascii)

800/720-3479 (v)

CustServ@massrelay.org

■ IP (Internet Protocol) Relay

IP Relay is basically old wine in new bottles. It circumvents the use of the telephone, TTY, and telephone fees, by letting you access relay service using your computer or other Web-enabled device, and an Internet connection. You access the IP relay by going to a web-page - AT&T, Hamilton, and Sprint are several of the IP relay services. The operator then dials the party you are calling using a voice phone. IP Relay also lets you use VCO and video relay. A computer has a far better keyboard than a TTY and the screen is much more readable and displays a larger chunk of your conversation.

A variant of IP Relay is found on several of today's smartphones, which have Internet browsers and allow the downloading of IP Relay software. This allows persons with no usable hearing to use their smartphone web browser to place an IP Relay call, a feature that comes in handy if your car breaks down far from home and you need to call a service truck to assist you.

Wireless Relay

Some mobile devices such as Sidekick, certain models of Blackberry and AIM mobile devices support wireless relay. See the Appendix for websites where you can check to see if your model is supported.

■ Video Relay Services (VRS)

Videophones (see Chapter 6) are of little use unless the people you call have them as well. Video Relay Services solve that problem. Meant to facilitate communication between a sign language user and a hearing person who doesn't use sign language, it interposes a video interpreter (VI) in the middle to relay the call. The deaf caller connects via the Internet to a video relay service and gives the VI, who stands in front of a camera, the number to dial. The interpreter signs what the hearing person says so the deaf person can see it on their screen, and then voices what the signing caller is "saying" to the non-signing user. The popularity of this type of relay is increasing.

■ CapTel™

For people who have used voice phones in the past, Relay has always been a necessary evil. It's slow and involves changing one's phone habits since only one person can speak at a time. Voice Carry Over makes it less sluggish, but still doesn't approach the

convenience of a voice phone. The recent introduction of Ultratec's CapTel™ captioned telephone, a variation on VCO relay, is the first development in telephone technology since VCO to benefit the hard of hearing/late-deafened population. And its audience is bound to become much broader. Anyone who can speak clearly can use a captioned phone, and more models and brands are bound to appear on the market.

The Ultratec system has been under development for many years. It's the answer to the perpetual question "Why can't we use speech recognition software to transcribe telephone conversations automatically?" Ultratec has developed a way that we can, but with an interesting wrinkle. As we mentioned before, the main problem with speech recognition software is that it usually needs to be trained to "understand" a single voice. And that's exactly what happens with the captioned phone. The CapTel operator repeats what the hearing person says into a microphone almost simultaneously. The software, trained to the operator's voice, transmits the words as text, which appears on the small captioned phone screen. The CapTel user not only hears the words through the amplified receiver of the phone but also sees them, after a short delay, on the screen. The user can use this transcript to fill in any gaps in understanding the voice call, and can also monitor the voice user's tone of voice. A deaf CapTel user can simply read the captions on the screen, as in a traditional relay call and just voice his or her part of the conversation. The operator is invisible and the voice user never knows that an operator is actually relaying the call. There are never any "Go Aheads" to type or voice. If the captioned phone user has poor vision, the phone can be hooked up directly to a computer screen using a USB cable.



CAPTEL

The situation is a bit more awkward when a voice user calls a captioned phone user. He or she must call the CapTel center and enter the number to dial. Otherwise, the operator never interacts with either user.

The CapTel phone can also caption messages on a voice answering machine or voice mailbox. Captioned phone service draws funds from the Interstate Telecommunications Relay Services (TRS) funds, as part of Title IV of the ADA (see Chapter 9 for more about this). CapTel can be used with a VoIP service such as Vonage.

In 2-line CapTel, one line becomes the voice line into which the user speaks, and the other is the CapTel line, which displays five lines of captions. Two-line CapTel eliminates the need for the voice user to first dial the CapTel center to place a call to a CapTel user. The voice user just dials the number directly, then waits while the CapTel phone automatically dials the captioning service to start the captions. One other advantage of 2-line CapTel is that the captioned phone user can turn captions on or off during the call; you can use call-waiting as well. The downside is that you will have to pay for the installation and fees for a second phone line.

What you need to take advantage of captioned telephone service:

- A CapTel phone from Ultratec. Once CapTel service gets off the ground in Massachusetts, the phones will probably become part of the Telephone Equipment Distribution Program (see Chapter 2).
- A single analog phone line for 1-line CapTel or two analog phone lines (with separate numbers) for 2-line CapTel. You can also use a DSL line with the appropriate filter, but CapTel will not work with a digital phone unless it has an analog port.

As we go to press, 43 states have adopted or in the process of adopting captioned phone service. In Massachusetts, the law is being considered for a second time by the legislature. Public support is very high, but the issue is complicated by the requirement of the state telecommunication law that all relay centers be within the state. At this writing, the only captioning center is in Madison, Wisconsin. Veterans, retired government employees, and members of native American tribes are the only people in the Commonwealth who can currently get CapTel through a federal program.

CapTel Numbers:

877/243-2823 (Toll-free Captioning Service/Voice)

888/269-7477 (Customer Service/Voice)

866/670-9134 (Customer Service/Spanish)

800/482-2424 (Customer Service/tty)

The FCC recently ruled that captioned phone service over the Internet, in which a special CapTel phone is not required, is authorized for compensation from the Interstate TRS fund that supports other types of relay as well. IP captioned phone service, which can use Skype, should be available by the end of 2007.

■ Short Message Service (SMS)

SMS is an inexpensive texting service that can be used with cell-phones or smartphones to send short text messages. You'll need an SMS-enabled phone. Messages are limited to 160 characters, though some carriers can take longer messages and break them into shorter individual messages to send. SMS is extremely popular in Europe, and Asia, but is just catching on in this country, where we do not use GSM (Global Systems for Mobile Communication), necessary for SMS, as much as other standards such as CDMA for wireless communication. Using SMS, you can send a message to another cellphone or computer. Your message can be delivered in a number of different formats: email, voice mail (to a landline phone using a voice simulator), and fax. You can also broadcast a message such as a traffic report to users within a particular cell area, or subscribe to a "premium" service that broadcasts information such as team scores or weather reports to your phone.

The user inputs a message using the numeric keypad on his cellphone. This has led to many abbreviations and many cellphones contain software to guess the word you are inputting and finish it for you.

■ Interpreters/CART Services

Although speechreading and assistive listening devices and systems may work well in a one-to-one or small group situation, understanding becomes far more difficult and stressful in situations where it is important to get every word accurately, such as a legal or medical appointment, and for lectures, classes, and speeches where the speaker is far away or on a raised platform, or simply doesn't speak clearly. For many years, late-deafened, severely hard of hearing, and Deaf people have been using Transliterators, Interpreters and, more recently, CART — Communication Access Realtime Translation — to translate or interpret the spoken word into a form of visual communication. Interpreters, Transliterators, and CART providers are highly skilled professionals who are paid by the hour at market rates. In most cases, they are paid by agencies, services, and businesses where the services are used. To find out more, visit www.mass.gov/mcdhh and click on **Interpreter/CART Referral Services** in the "What We Do" module in the upper left corner.

CART Service and/or Interpreters and Transliterators can be used in practically any setting where spoken communication needs to be

visually accessible, for example, in adult education, college, and elementary or high school classes; lectures; court; meetings with attorneys, accountants, doctors, insurance brokers, construction contractors, car dealers, investment consultants; in senior centers; rallies on the Common; theater performances; marriage counseling; on-the-job training; performance meetings with the boss; weddings and wedding receptions; funerals — virtually wherever access to communication is needed.

Referrals for both types of services are handled by the same department. We discuss the different services, as well as their remote counterparts, more fully below.

MCDHH Interpreter/CART Referral Service

617/740-1600 (v)

617/740-1700 (tty)

617/740-1880 (fax)

Toll Free: 800/530-7570 (tty)

Toll Free: 800/882-1155 (v)

8:45 a.m. - 5:00 p.m., M-F

For medical, mental health and legal emergencies only:

800/249-9949 (v/tty)

24 hours a day, 7 days a week

You can also print out an interpreter, medical interpreter, or CART request form at the MCDHH website: www.mass.gov/mcdhh under “Key Resources” on the homepage. Check this website before calling to request an interpreter; it tells you what information you will need to tell the referral specialist.

CART Service

Communication Access Realtime Translation (CART) Service is one type of “interpretation” or translation which is often the choice of deaf or hard of hearing individuals who read English fluently, do not use or are not fluent in sign language, and who usually also have understandable spoken language. CART Service provides a visual text with nearly instantaneous trans-



Stenotype Machine used for CART

lation of the spoken word. The CART provider types the speaker's words on a stenotype machine, which is connected to a notebook computer equipped with software that translates the stenographic code into English. The deaf person can read the results in plain English text translation on the screen of the notebook computer, or on a larger monitor plugged into it. For larger group events, the text can be displayed on a large video screen or projected on a wall screen.

CART Reporters are professional court reporters with very good "realtime typing skill" and special training about deafness and how to provide translation service for deaf people. They have received special training and certification and adhere to a strict code of ethics and confidentiality. Because they "type" in a phonetic shorthand, CART Reporters can type at speeds of 225 words per minute, which is average speaking pace. By comparison, most Telecommunications Relay Service operators are only required to type at 50- 65 words per minute, which is as fast as data can be transmitted on a TTY.

CART Service is an excellent choice for group meetings; even hearing people appreciate the convenience of not having to strain to catch poorly articulated or amplified words. For conferences, CART/Video Projection Service, which projects the captions above or below an image of the speaker, is ideal, since it lets the listener read the transcript and speechread the speaker simultaneously. MCDHH also provides CART free of charge to support group meetings held by organizations such as the Hearing Loss Association of America (HLAA), the Association of Late-Deafened Adults (ALDA), and Minuteman Implant Club.

How Do I Arrange for CART Service?

- To request a demonstration of CART Service, call MCDHH.
- To obtain CART service, the agency or individual who is paying for the service should call the MCDHH's Interpreter/CART Referral Service at the numbers listed above, or fill out an online request form on the MCDHH website.

Since demand for this service has been rising steeply, you should call well in advance. If you want notes from the session, you may be able to arrange in advance with the CART reporter to get a diskette. Plan to provide the reporter with a list of names of people who will be speaking, technical terms, acronyms and other words that

should be entered into the software dictionary. During long meetings, remember to schedule a break; CART reporting is very intensive work. Sometimes at very long events, two CART Reporters work together, taking turns.

■ Remote CART

Unfortunately, there are never enough CART providers to go around. The job pays quite well and can be extremely rewarding, but it also pays far less than court reporting or working for a private corporation. Those CART providers who are under contract to MCDHH must meet strict criteria and are busy to a great extent working for students in college classes, which is a tremendous time commitment. Many meetings and appointments that could benefit from CART do not get the opportunity. As a result, companies that supply remote CART have sprung up and are starting to ease the shortage of local CART providers. If you wish to use remote CART, you'll need:

- A computer with an Internet connection in the meeting room. It should be running remote captioning software. (Alternate methods use streaming video or a telephone connection.)
- A high-speed Internet connection is recommended.
- A good conference telephone

The remote CART provider can hear the proceedings of the meeting picked up by the conference telephone in the meeting room. She types what she hears on her steno machine; it is processed by the software installed on her computer and sent to a display in the meeting room.

■ Interpreters/Transliterators

For late-deafened adults who are able to use ASL or signed English, or who are competent speechreaders, using an interpreter or an oral transliterator may be an excellent way to handle communications at important meetings and conferences. MCDHH has an Interpreter Referral Service and is active in the approval process for interpreters.



Commissioner Heidi Reed of MCDHH using Interpreters

For our purposes, there are several different types of Interpreter:

- ASL Interpreters interpret spoken English into American Sign Language and interpret ASL into spoken English. One must be fluent in ASL to use an ASL Interpreter.
- Signed English Transliterators translate spoken English of the hearing person into mouthed (no voice used) English supported by signed English for the deaf individual. They also translate the signed English and spoken English of the deaf person into standard spoken English. One must learn signed English or ASL to use this type of interpreter effectively, although good speechreaders sometimes find it useful to watch a Signed English Transliterator in a meeting.
- Oral Transliterators soundlessly and very clearly mouth the words of the speakers. Extensive training enables them to present a very visually clear model of what is being spoken for the person with the hearing loss to receive, paraphrasing when necessary for words that are not visible on the lips. The Oral Transliterators may also voice the message and intent of the speech and mouth movements of the person who is deaf or hard of hearing, so that the hearing person can understand. The deaf individual must have good speechreading ability to take advantage of oral transliteration.

Interpreters, Transliterators and CART Reporters are all professionals who have had special training and hold certification. They have a strict code of professional ethics and are sworn to confidentiality about any and all information about their assignments and the communications exchanged during those assignments. When you call MCDHH for a referral (see above), you should specify location and time of the event, the topic, preferred mode of communication, who will attend the event, and names of preferred interpreters, if you wish. Some interpreters have expertise in specialized areas, for example, medical, court, or legal settings. Try to make arrangements well in advance, since the demand for interpreters is greater than the supply.

For Hearing People: How to use an interpreter

- Speak at your natural pace. The interpreter must hear a complete thought before signing it.

- Look at the deaf person and speak directly to him or her. Never say, “tell him” or “tell her.”
- Stand or sit opposite the deaf person and next to the interpreter, if possible.
- For meetings in large rooms, try to reserve seats in the front for people who will be using the interpreter, so they can see more clearly.
- Remember that the deaf person must be able to see the interpreter’s hands and upper body. Make sure the interpreter is visible whenever slides or movies are shown.

Video Remote Interpreting (VRI)

The bad news is that interpreters are in even shorter supply than CART providers. Not only do more deaf people use interpreters, but they are also used at all levels of education. In addition, the recent popularity of video relay has drawn many interpreters from the pool for permanent full-time employment with agencies providing this service. As with CART, help has arrived with the advent of remote interpreting (also known as distance interpreting). If you’ve been reading this chapter, you can probably predict how this works. Using a computer, webcam, and microphone at each end, the interpreter hears the voice speaker through the meeting room microphone and signs what is being said just as an interpreter in the room would, but in front of a webcam. The picture appears on a computer at the deaf person’s desk or table. When the deaf person signs, the interpreter watches and voices through a microphone for the hearing users.

Deaf-Talk

Deaf-Talk is a VRI system reportedly used in about 350 hospitals across the country. Developed by a company called DT Interpreting, the system uses a Sony compact video conferencing system on a cart that can easily be moved from room to room. The hospital phones an 800 number and is connected to a remote interpreter who can both see and hear the patient and doctor, and interprets for the patient. This can avoid the expense and delay of waiting for an on-site interpreter, but some deaf people have complained that the system does not work if the patient is lying down and should not take the place of a “live” interpreter.

Deaf-Talk is now in use in the following Massachusetts hospitals:

Holyoke Hospital, Holyoke

Bay State Medical Center, Springfield

U Mass. Medical Centers (Memorial and University), Worcester

Boston Medical Center

Cambridge Health System

Boston Children's Hospital

St. Elizabeth Medical Center, Brighton

South Shore Hospital, South Weymouth

Good Samaritan Hospital, Brockton

St. Anne's Hospital, Fall River

Cape Cod and Falmouth Hospitals

The list continues to increase, so check with your local hospital.

Note-takers and Computer-Assisted Notetaking (CAN and C Print)

When CART is unavailable or too expensive, you may be able to turn to note-takers. These can be professionals or volunteer classmates or co-workers. They can take notes by hand, or they can type them on a computer, to be read from the screen (this is known as CAN, Computer-Assisted Notetaking). Because note-takers don't use shorthand, it isn't possible for them to provide verbatim transcription; instead, they summarize the proceedings, much as you would if you could hear and were taking notes yourself. CPrint, a hybrid of CAN and shorthand abbreviations, does not provide verbatim accuracy as does CART, but may provide more information than CAN's summary of key points. Keep in mind that there are many situations where putting yourself at the mercy of a note-taker is essentially relying on someone else's grasp of what is important in any given situation. If an absolutely faithful rendition is needed, CART is still the way to go.

■ Captioning

In the last chapter, we discussed infrared devices that amplify television volume. These are, of course, only useful for people who have some residual hearing. Captioning is a solution with a far broader audience.

Captioning: Open and Closed

Captioning has made many television programs, movies, and even video clips on computer software (like Microsoft Encarta) accessible to millions of deaf and hard of hearing people. Although the end result is much the same, the two types of captioning differ in the way they are displayed on the screen. Both display the audio part of the movie or broadcast as text at the top or bottom of the screen. Open captioning resembles two- or three-line subtitles, such as those used in foreign language films. No special equipment is necessary to view the captions and everyone in the theater can read them. Some theaters show open captioned films (the Appendix lists information about Insight under Chapter 9). Open captioned films for home use are distributed by an organization called the Described and Captioned Media Program (DCMP), which is funded by the U.S. Dept. of Education and administered by the National Association of the Deaf (NAD). Membership in the program is free. The video library has over 4,000 titles, both captioned and, for the blind, described. Films can be borrowed for a week, and DCMP pays postage both ways. Closed captioning looks the same, but can only be viewed by turning on a captioning “decoder” or using a technology such as Rear Window Captioning (see below) that lets only the user view the captions.

Captioning videos and broadcasts is very similar to CART, which we discussed in the last section. For live television broadcasts, captioning is done in real time. The captioner may be in the studio or may receive the audio over the telephone or Internet at a remote location. For movies and taped programs, captioning does not need to be provided in real time. The captioner can backtrack to review a passage, and accuracy can be far higher.



Photo credit: Off-screen print courtesy of The Caption Center in Boston. Copyright 1990 Paramount Pictures Corporation. All rights reserved.

In 1972, the WGBH Caption Center in Boston captioned the first nationally broadcast television program, supported by funding from the Department of Health, Education and Welfare. The program? Julia Child's *The French Chef*. Since that time, captioned telecasts have increased dramatically. During most of that period, it was

Star Trek: The Next Generation is one of many captioned programs available on television to deaf and hard of hearing people.

necessary to have a small “decoder” to display closed captions. However, since July 1993, every television set manufactured or sold in this country with a screen 13 inches or larger has been required by law to have built-in circuitry to display closed captions. Different manufacturers use slightly different variations, but in general, you turn captioning on and off using the remote control or through the setup menu.

For those who wish to caption their own videos, the Carl and Ruth Shapiro Family National Center for Accessible Media (NCAM) at WGBH distributes two free software programs:

- MAGpie is a captioning program for students and their teachers
- CC for Flash adds captions to Adobe®Flash® files

Most major release rental videos are now closed captioned, and many oldies are also being distributed with captions. Look for the closed captioning symbols on the

back of the box.



■ Rear Window Captioning (RWC)

According to popular notion, hearing movie-goers find open captions distracting and do not want to see them. Several different systems have been tried to deliver closed captioning to people with hearing loss without annoying hearing viewers. There have been special eyeglasses and captions displayed on the back of seats ahead of the viewer. Rear Window Captioning, developed by Larry Goldberg and Dan Glisson of WGBH and filmmaker and inventor Rufus Butler Seder, has emerged as the favorite system. In RWC, a large LCD display is mounted on a back wall of a theater. It displays captions backwards. Viewers receive a reflective plastic unit as they enter the theater, mounted on a stand or a gooseneck that attaches to the cupholder on their seats. They sometimes have to sit in a particular part of the theater. The user adjusts the reflector so that it displays a mirror image of the backwards captions on the rear wall. The main complaint about Rear Window Captioning is that the user must shift between the screen and the reflector to follow the performance. The Appendix provides a list of MoPix® theaters in the state that have RWC.

Captioning and Universal Design

Captioning is a prime example of how intelligent design features intended for one audience can, in fact, find favor with other segments of the population. Captions have been found convenient and useful by people who aren't deaf or hard of hearing: children learning to read, people learning English as a second language, television viewers who don't want to bother others in the room, patrons in noisy bars, restaurants and health clubs who wish to follow the action on widescreen televisions and monitors. This is a good example of how universal design, an effort to develop products that can be used by people with a wide variety of abilities in many different circumstances, can benefit everyone.

In this chapter, we've touched on some technologies and services that can help you in real life. We'll continue and broaden the discussion in the next chapter.

8. HELPING YOURSELF

■ Strategies for Daily Use

In addition to seeking help from other individuals, groups, services, and technology, we must also take the initiative to help ourselves. We must become teachers, students, and advocates. One can almost hear John Houseman of Smith Barney advertisement fame intoning, "Late deafness has its responsibilities."

Become assertive

Learn to ask for accommodations and assistance. Tell people how they can help you communicate better. Contact event organizers well before the event to discuss communications access; it may be something they haven't considered. This is a classic example of "If you don't ask, you don't get." Easily said, I know. Asking for help is not The American Way. But deafness is invisible. You cannot expect people to change the way they communicate unless they know you're deaf, and you cannot expect them to know that you're deaf unless you tell them. This is one of the instances when support groups can be very valuable. If you feel uncomfortable being assertive, speak to others and find out their tricks of the trade. Some groups even have assertiveness training sessions where you can get the opportunity to role-play and test out different approaches. The more you practice assertiveness, the more you refine your technique and the easier it becomes. Jane Sokol Shulman tells of meeting with her professors each semester to tell them about her hearing loss (she was severely hard of hearing at the time) and explain what they could do to help her follow lectures and class discussions. "By going through the process of speaking to my professors, by using the words hearing impaired...I got used to the words, I got used to the ideas. At first, of course, I cringed every time I had 'the talk,' but after a while it got to the point where I could do it calmly."

Remember that few hearing people know much about deafness. They may, in fact, have many misconceptions about the best way to help. You will have to teach people about deafness and what they can do to make communication easier. Once people know more about deafness, many will go the extra mile for you. In a message on the Beyond Hearing online discussion group (see Chapter 2)

many years ago, Muriel Bartholomew recalled her daughter's wedding. (Muriel was totally deaf at the time and had not yet received a cochlear implant.): "I was absolutely stunned...when the bride and groom took their vows FACING the congregation while the pastor's back faced the people. It was a total surprise to me and I was able to read the young couples' lips as they said their vows." A small point, perhaps, but a kindness that gives that warm, fuzzy feeling.

You will have to be a constant advocate for your own communications needs, in your family, at your job, when you participate in activities you enjoy. For example, Ginny Mazur, a member of the Greater Boston chapter of HLAA, lamented the fact that she couldn't attend accessible films at her local cinema. She discovered that the management, which had brought some of the first open-captioned films to the area many years ago, was open to her proposal to create an accessible movie night. Working with the Boston Guild for the Hard of Hearing at Northeastern University, the theater installed an audio loop system in a small screening room and has been showing closed-captioned films once a month for a dedicated film club. Later in this chapter, you'll find contact information for this Deaf and Hard of Hearing Film Club, as well as where to find listings of captioned movies elsewhere.

Make your environment communication friendly

We've already discussed (see Chapter 4) some of the things you can do to optimize conditions for spoken communication in your home and place of work. They bear repeating:

- If you depend on residual hearing for comprehension, use sound-deadening materials to make bare rooms more quiet. This can be done using carpeting, drapery, even sound absorbent ceiling tiles.
- Re-position furniture and/or room lights to create a better environment for speechreading. For example, place your own seat so that the back is against a window, so that when you have company the light will be on their faces, not in your eyes.
- Install alerting and signaling devices so you know what is going on in your home environment.
- Make use of TTYs, telephone relay services, and other communication technology

Carry a pad and pen

When all else fails, you can always resort to a pad and pen, but you'll have to carry them with you. There is nothing worse than hunting for a scrap of paper in the middle of a conversation. If you or your conversational partner have a cellphone or smartphone, you can also ask the person to type out words that you're simply not understanding.

Relax

Don't attempt the impossible. When you're deaf, spoken communication can become an exhausting and stressful process. Try to plan your days to include time for rest and relaxation. Schedule important appointments when you know you'll be fresh. Most important of all, don't be hard on yourself when you're in impossible communication situations. Part of any successful coping strategy is realizing when things are hopeless, and not fighting them.

As Kim Grebert, a deaf expert on hearing loss and stress who gives frequent workshops, has said, "We (people with hearing loss) work so hard to make communication exist, no wonder we're stressed." Stress affects us physically. Our initial "fight or flight" reaction may help in the short term as our bodies respond by pumping out chemicals that raise our heart rate and blood pressure, tighten our muscles, and make our brains work faster. We're always on "high alert" for visual cues. All this, as well as the stresses of modern life, contributes to a sense of fatigue, powerlessness, and physical illness. Grebert advises, "Breathe deeply from the belly, exercise, meditate, slow down, sleep, eat healthy foods, take care of yourself." Be clear about your priorities and distribute your energy accordingly.

A few years ago, when my dog graduated from obedience class, I decided it was a good excuse to celebrate, and invited a few friends to drop by afterwards for cake and coffee. My dog loves company and is very lively and sociable, often to the point of becoming a nuisance. But that night, having performed during class and been very excited over company for half an hour, she decided that she'd had enough and crawled under an end table in a corner and went to sleep. Every now and then, when I've overextended myself and following conversation becomes too much of a burden, I have to stop and ask myself, "Why aren't you as smart about this as your dog?" There are times when we just cannot muster the energy and concentration necessary to follow spoken communication - or when the

environment is so inhospitable to communication that any attempt is almost certainly bound to fail. Don't keep beating your head against the wall. Make your apologies (probably not as effective as wagging your tail, but it's the best we can do) and fade into the background, or move to a quiet corner for a while.

Cultivate your sense of humor

You're going to encounter some strange situations and predicaments in your life that directly relate to your hearing loss. It's best to keep your sense of humor available to deal with those when they arise. Although you may not meet the legendary waitress who hands you a Braille menu when you tell her that you're deaf, you'll definitely get some bizarre reactions. It's best to have patience and laugh. Try — and it's hard, I know - to remember that the other person is uncomfortable with the situation and probably embarrassed. You'll inevitably meet at least one irritable worker who will growl "Are you deaf?" Stop him in his tracks by looking him straight in the eye and saying an emphatic "Yes." It's always a showstopper.

Vote with your feet and pocketbook. Always remember that 10% of the population has a hearing loss and there is no reason to be treated like a second-class citizen. Patronize and reward those who make your life easier and more pleasant; avoid those who don't.

Become an advocate

If you're looking for Battles to Wage or Good Works to do, you've come to the right place. The Deaf, late-deafened, and hard of hearing population has made great strides in the past few years, but we're still at the beginning of the road. Because hearing loss is invisible and isn't life-threatening, it's easy for legislators, corporations, employers, and providers of services to overlook issues related to it. There are many causes to campaign for and each of us has favorites:

- **Accessibility:** We'll discuss the Americans with Disabilities Act and its requirements in the next chapter. You can lobby for CART and interpreter services, scripts, and assistive listening devices in public places.
- **Captioning:** Many late-deafened people have found that their letters and phone calls have brought about more hours of captioned telecasts. Don't forget to send a note of thanks to the station (and even to the program sponsor) when it sees the light. Conversely, if captioning is awful or nonexistent, write a

letter pointing out that you are a loyal viewer but that the lack of professional captioning standards is turning you towards the competition.

Less than 1% of all movies shown in commercial theaters are captioned. "The Coalition for Movie Captioning (CMC) is a consortium of the major national organizations of deaf or hard of hearing people. CMC addresses the theater access needs of 28 million deaf, hard of hearing, late-deafened and deaf-blind consumers. CMC's goal is to make all first-run movies accessible to people with hearing loss. CMC's member organizations are the Alexander Graham Bell Association for the Deaf and Hard of Hearing; Association of Late-Deafened Adults; Deaf and Hard of Hearing Consumer Advocacy Network; Deaf Seniors of America; League for the Hard of Hearing; National Association of the Deaf; Self Help for Hard of Hearing People, Inc.; and Telecommunications for the Deaf, Inc."

- **State Legislation:** Right now, there are several critical pieces of legislation at the State House, among them a bill that would amend the telecommunications law to make captioned phone service (CapTel, mentioned earlier) available to deaf and hard of hearing people in the state. We can always advocate for budget increases for MCDHH, whose budget has remained fairly static in the 20 years of its existence, and to increase the budget of the independent living centers. Your support can make a difference. The first edition of this book was produced through funds allocated to the Massachusetts Commission for the Deaf and Hard of Hearing as a result of advocacy to the legislature by members of the Association of Late-Deafened Adults. Since then, MCDHH has picked up the tab for each reprint and revision. We've seen a law passed to require newborn screening for hearing loss, another that required hearing aid dispensers to be certified and responsible to a board of examiners. These laws were passed because people like you advocated for them.

There will continue to be many possibilities for action in the political arena. You may wish to take a look at the website (www.dpcma.org) of the Disability Policy Consortium, "an organization of volunteer disability rights activists who share a

common goal of equal opportunity for all individuals with disabilities.” Also, the MCDHH website (www.mass.gov/mcdhh) has information about current pending legislative bills.

- **Insurance Coverage:** Many health insurance plans now cover the cost of cochlear implants. But very few cover the cost of routine audiograms and hearing aids. Again, your voice can make a difference.

Life is full of small annoyances that sometimes only need to be brought to the attention of organizations and manufacturers. In the first edition of this book, for example, we reported that a member of Self Help for Hard of Hearing People (SHHH) in Montana received a Black & Decker breadmaker as a gift. It arrived with recipes, instructions, and a videotape that showed how to use the machine. But the videotape was uncaptioned and therefore useless to the woman. She wrote to the company and requested a captioned video, or, alternately, a transcript of the tape. Black and Decker arranged for a transcript from the production company in Canada and she had it within two weeks. She wrote to us to identify herself after picking up this guide at the SHHH convention in Boston.

■ Try new modes of communication

Take a class in speechreading and/or sign language (see Chapter 2). Practice with friends or at meetings and social events. Learn the benefits of using a TTY and the Telecommunications Relay Service (TRS), fax machines, and email. (See Chapters 6 and 7.)

And, if you learn sign language, you’ll discover that many recreational activities are interpreted: theater events, museum lectures, even musicals.

If you’re curious about Deaf culture, contact a DHILS Program (an Independent Living Program, providing services for Deaf, late-deafened, and hard of hearing people; see the list on the MCDHH website). You may meet other people who share your interests and will help you become fluent in sign language. You can also find frequent informal social gatherings in the state where attendees practice their ASL skills. Even if you’re not interested in learning sign language, knowing the fingerspelling alphabet is very useful as it allows you, your family, and friends to get past those “impossible” words by the simple expedient of fingerspelling them.

Work with your hearing aids and assistive listening devices

If you use hearing aids or assistive listening devices, help them to help you. Before you do anything else, it is important you adhere to the break-in period suggested by your hearing healthcare practitioner. Practice with them, at first in quiet and comfortable surroundings; when you have become comfortable then venture out into different settings. Learn what works and what doesn't. Consult with your audiologist or hearing aid dispenser to optimize them for your particular needs. It's an ongoing process. If you're having difficulty with certain situations or equipment, post a message on a computer list such as bhNEWS or Beyond Hearing (see Chapter 2). And of course, there are always search engines such as Google. With some 28 million Americans with hearing loss, odds are that you're not the first person confronted with a particular problem or issue. You'll find many people who can brainstorm with you.

■ Join a support group, meet new friends

As we've seen, members of ALDA, HLAA and other support groups (see Chapter 2) frequently come to think of their groups as "extended families." They're brought together by hearing loss, but stay together because they find other interesting people in the groups. Many of these support groups hold annual national and regional conferences, another way to have a vacation and enjoy relaxed communication, to make and meet friends in a communication-accessible, stress-free atmosphere. If that weren't enough, these conventions also attract specialized manufacturers who showcase the latest and greatest in "accessible deaf products" and sometimes conduct workshops and focus groups.

The same holds true for computer forums and lists. I've attended conventions where I've met a number of members of the Beyond Hearing list (we call ourselves BHers, or Beyonders) with whom I'd been exchanging email for years. I've met Beyonders from as far away as Australia, as well as many others from across the country with whom I've corresponded for years.

■ Find new activities and interests

You'll be surprised at the number of activities that don't require hearing. Hearing isn't necessary for most sports (although you'll probably miss out on trash talk on the basketball court). Try walking or hiking, cycling, jogging, swimming, riding, boating (no one can

hear above the noise of the motor, anyway), golfing, skating, water- and snow skiing. And there are any number of other activities to try: writing, reading, painting, antiquing, pottery, knitting, weaving, cooking/baking, sewing, gardening, going to museums, keeping up written or computer correspondence, surfing the Net, yoga, and meditation. The list is endless.

Just be aware that for some activities, if you do use hearing aids for awareness of environmental sounds or to supplement your speechreading skills, it is probably a good idea to either take them off or use “disposable” spares (usually an old hearing aid that you’ve hung onto that still works) in situations where you **MUST** hear but the risk to the hearing aid from water, sweat, or impact is great.

Here are some of the organizations you may wish to contact: •

VSA Arts of Massachusetts (VSAM)

“Serving individuals with disabilities by creating opportunities for participation in the arts and integration into the cultural and educational mainstream.” VSAM produces “Access Expressed New England!: A Cultural Resource Directory” featuring over 300 plus accessible venues and resources throughout New England. The guide can also be found on-line at: www.accessexpressed.net/

- Deaf and Hard of Hearing Film Club

“Our monthly film club spotlighting contemporary features and documentaries with a special focus on the needs of those with hearing disabilities. All films are shown from DVD in the 45-seat Screening Room, which is equipped to be compatible with telecoil (T-coil) hearing aids. Headphones that are linked to the T-coil loop are also available for those without T-coil hearing aids. In addition, films are shown with closed captioning.”

- Insight Cinemas

Provides Open Captioned films at selected times in certain theatres.

- Access News: Movies Captioned & Audio-Described (MA)

Jan Meyer compiles a weekly list of captioned movies. To subscribe, send your email address to her at Jtm591@aol.com

- “MoPix Update”

This is a weekly listing from WGBH's National Center for Accessible Media (NCAM). Mary Watkins, Outreach Director, sends out news of all current and future movies with Rear Window Captioning and DVS audio-description (see Chapter 7).

■ Perform a reality check

Finally, if you seem to be constantly in conflict with people, or feel like you're being isolated, it may be time to analyze what's happening. For one thing, it's very easy to cross the line from assertive to aggressive. For another, it's easy to let your anger over your deafness, if that's still an issue, taint completely unrelated episodes or activities.

I once knew a woman who had begun to lose her hearing as a teenager, became late-deafened as an adult, and was now working as a librarian at a school for the deaf. She was active in the Deaf community, well respected by her co-workers, and was fluent in ASL. But she still seemed enraged at her parents, who had insisted when she first began to lose her hearing that she remain in a mainstream classroom.

She had never been able to resolve that issue with them and seemed to need to create conflicts with others so that she could vent her righteous indignation. When she traveled with her hearing dog, she left his identifying leash behind, then walked boldly into the ladies' room with him, apparently looking for a confrontation (and often finding one). Because he was a service dog, he was legally entitled to this privilege, but no one could tell that he was a service dog. She became furious whenever a hearing person spoke to her while her back was turned, but refused to tell people that she was deaf and how best to communicate with her. A number of us listened in dismay to her stories of run-ins with various strangers. We tried to tell her that she couldn't expect people to be mind-readers, that they would be happy to meet her halfway, but that she had to take the initiative and teach them. “I spend all day teaching,” she replied. “I don't want to have anything to do with it when I'm on my own free time.” I've always been sorry that we weren't able to help this very bright and talented woman understand that certain chores come with the territory and that she was behaving in an unreasonable and manipulative manner. Learning to be deaf can be difficult.

Like it or not, you're an ambassador for people with hearing loss. How you behave colors the way hearing people regard all people with hearing loss.

Living well with deafness isn't much different from living well with anything else. A great deal depends on attitude. Is the cup half empty or half full? Do you think that most people are eager to oblige or are they totally self-absorbed and uncaring? Is deafness a challenge or a burden? I've found that our expectations are usually fulfilled. I've been touched many times by the kindness of even the most casual acquaintances: the doctor who trims his mustache before my appointments so that I can read his lips more readily; the associates who volunteer to take notes for me at meetings; the people who send me clippings; the friends who make sure I can follow the conversation at the dinner table. When your ears fail, you can still look around and find much goodness in the world.

9. REAL LIFE COPING

Each of us develops a personal “style” for handling difficult communication situations, but it’s helpful to observe and learn how others cope. In this chapter, we’ll discuss some common scenarios.

■ Explaining Deafness to Hearing People

One of your first tasks will be to develop a short spiel to explain your deafness to hearing people with whom you come into contact. You’ll want to give people some guidelines for talking to you, for example, “I’m deaf and I speechread. I need you to speak more slowly, face me, and please don’t yell.” Some people will also need an explanation of the nature of your hearing loss. This is fairly easy if you’re deaf as a post. If you have some residual hearing and wear hearing aids, it becomes more difficult. After several years of explaining to people that my aids do not correct my hearing the same way my glasses correct my vision, that I hear them speaking but that I understand them about as well as if they were speaking Tibetan, I’ve recently switched to a briefer version. I now tell people that I just don’t hear the consonants in most of their words. Since few people have thought about consonants since the third grade, it definitely makes them pause and think. If that fails, and you are already keenly aware that communication will be impossible because of environmental factors, you can always simply point to your ear, shake your head, and mouth “I’m deaf.”

■ Telephones Revisited

We’ve already discussed some of the telephone devices and workarounds you can use: TTYs, Relay service, telephone amplifiers, signaling devices, fax machines, email, etc. For those of you who haven’t completely abandoned the voice telephone, or sometimes need to understand voice messages on an answering machine, here are a few additional tips.

Answering Machines

Put directions for calling back via Relay in an answering machine message: For my cottage rental business, I’ve had little success with this, but my outgoing message is already overly long and includes many, many directions. You may have more luck on a strictly personal phone line; I’ve found that most business callers know nothing about either TTYs or Relay services and aren’t about to learn from a

30-second answering machine message. Since many of my business calls are from out of state, callers are also understandably reluctant to make yet another long distance call to reach me using a contraption they couldn't distinguish from a head of lettuce.

So what do you do when someone leaves a voice message on your answering machine? While we're all waiting around for speech recognition software to come of age and put our answering machines out of their misery, the best solution is probably to use the telephone company's Call Answering service, if it's available in your area and will work with your phone system. You can then have a Relay operator call your mailbox and transcribe the message for you. If that isn't a possibility and if no hearing members of the household are present, you'll have to get creative. My personal solution has been to stick with the older type of answering machine that still records a message on a standard size cassette. I then pop out the cassette, put it in a handheld tape recorder, and either play it over the relay to a hearing friend, or grab a pen and pad, and wander through my building looking for a neighbor who can play secretary for me. This has its limitations; I once found myself at midnight asking a total stranger I met in our parking lot to listen to a message. It turned out to be a call telling me that an aunt had died, and it was a tossup which of us was more upset. The next day, before leaving for New York for the funeral, I arranged to get a separate distinctive ring number for the TTY so I could leave it on auto-answer mode to take emergency messages.

If you have a computer, you can always use IP Relay to call your telephone line and retrieve messages; this is ideal because it does not require that you have a second phone line.

Distinguishing Numbers and Letters

Although I hate to do it, if the voice phone rings when I'm home, I'll take the call and pray a little. Even these days, I sometimes have trouble distinguishing a Yes from a No over the phone; my current technique is to call back using the Relay. The problem then becomes how to get the caller's number if it doesn't register on my Caller ID unit or if I'm at a different extension. In my pre-implant days, the only numbers I could understand with a fair degree of accuracy were 0 and 7 (since they both have two syllables), I've had good luck asking people to count out each digit, for example, if the first digit is a 4, to say "1-2-3-4." I may not be able to understand

the numbers themselves, but I can tell when the counting stops. You can do the same thing with letters, or make up your own alphabet:

“Was that B like in Butterfly, A like in Appendix, R like in Rhinoceros, and T like in Tiddlywinks?” Make up your own custom alphabet with friends, using words of two or more syllables that are unique.

A is for Artichoke

B is for Balderdash

C is for Crustacean

D is for Dynamite

E is for Elephant

F is for Fiddlesticks

G is for Galaxy, etc.

Shopping

“Where are the canned peaches?” can become a major research project when you’re deaf. If you can’t seem to locate the canned fruit department using the overhead signs on aisles, the best method of getting an answer may be to ask an employee to show you the number of the aisle by holding up the appropriate number of fingers. Some supermarket employees will welcome the respite from stacking boxes of corn flakes and lead you to the peaches. Or you can carry a pad. At the register, you can usually position yourself so that you can see the total. Another strategy is to pay with large bills and not worry too much about hearing the precise amount. This calls for a bit more trust than I can muster.

In supermarkets and other large stores, it’s important not to forget that the sales people are there to help you, though they sometimes lose sight of the fact. Remind them. Some chains have experimented with shopping carts that can actually lead you to what you’re looking for or display a map of the store and your current location relative to the item you are looking for, on an LCD on the handle.

■ Doctor's Offices and Hospitals

Strangely enough, the medical profession as a whole seems to find it almost impossible to deal intelligently with people who are deaf. Why does the nurse always call your name to summon you? Unless you want to spend the entire time you're in the waiting room in a state of high alert, you'll have to explain that you're deaf and tell the receptionist that you won't hear anyone call your name. It's then their problem, but you can help things along by sitting where you can easily see and be seen by the nurse. Of course, even then, things can and do go wrong: Jonathan O'Dell recently had an appointment in a large doctor's office. He told the receptionist that he would need someone to walk over to him in the waiting room to call him. Imagine his frustration when the assistant opened the door, stopped, and called out something unintelligible repeatedly. It wasn't until all the other patients in the room began to look at each other that he realized that this must be for him. When he inquired, a little upset, why his instructions had not been followed, the assistant showed him what the receptionist had written on a sticky paper: "Get him". How the receptionist expected an assistant to "get" someone she had never met before remains a puzzle.

If you need an interpreter or CART service to communicate at your medical appointment, be prepared for a battle. Unless you're dealing with a large hospital, most doctors are reluctant to foot the bill for interpreter services, although they have an unequivocal responsibility to do so under the Americans with Disabilities Act. You can also ask them to get the Deaf-Talk system we described in Chapter 7, or SNR or Ubi Duo (see Chapter 6). Alternately, you may be able to get by with a notebook computer on which the doctor types his replies.

When making an appointment with a doctor over the phone, always repeat the date and time to double-check, to make sure that you heard it properly or the relay operator typed it correctly.

If you are planning elective surgery and know you will be in the hospital, make plans for an interpreter or for CART well in advance. You can alert the hospital to any difficulty you may have communicating and have your family place a banner over your bed telling people to face you on the side of the bed away from the window and to be sure the lights are on when it is dark, because you lipread. If you wear hearing aids or a cochlear implant, speak to the hospital beforehand and ask if you can wear them during surgery or if they'll be kept close at hand so you can put them on in the recovery room. I kept my implant on while

undergoing knee replacement surgery recently and was able to talk to a member of the anesthesiology team during the surgery. If that isn't possible, it may be possible for a nurse to write notes to you on a pad if you're awake.

■ Restaurants

When was the last time you were able to hear the name of the soup du jour? Dining out is usually a major challenge. If you have some useful residual hearing, start by asking for a table away from the kitchen, fan noise, and any amplifiers for music. I have a friend who restricts her dining to a list of restaurants with quiet corners. Explain to the waitperson that you may have difficulty speechreading and want him or her to write down information delivered orally, such as choices of soup, vegetables, salad dressings, and pies. Most waitpersons will be happy to comply, if for no other reason than to expect a larger tip.

At the table, you may want to seat yourself so that you are in the middle of the group and can face as many people as possible. If the candle or flowers block your view, re-locate them. If you can use an assistive listening device, it may help, particularly if you can pass the microphone around to the speaker. You may also have a directional microphone setting for your hearing aids or a program that quiets background noise. Otherwise, your conversation will probably be limited to your near neighbors — unless you learn sign language and are with a group of people who can sign. I use a directional microphone connected to my processor in restaurants; I tend to hear better than my hearing friends when there is background noise.

Fast food drive-thru windows represent another hurdle. A number of restaurants now have display screens at the ordering station that show the items you have ordered and the total cost of the meal, but many do not, or their systems don't work. You can go inside to order, of course, but that would be a moral victory for the restaurant. The best approach would seem to be to place your order slowly and clearly, repeat it slowly and clearly, then tell The Voice at the other end, "That's it. I can't hear you and I'm moving up." If you're creative, you may be able to come up with something more original. And if you can't even hear the squawking of the intercom, you'd better be creative. A number of years ago, **ALDA News** editor David Coco described how he used the amplifier of the order station as a tactile aid at a drive-thru hamburger joint in Texas. "A well-trained finger

[placed on the speaker to sense vibrations] can easily distinguish between a hamburger, which is buhbuhbuh and a double cheese-burger, which is buhbuh buhbuhbuh. If you have any doubts about your “finger reading” ability, however, just repeat your whole order twice and cross your fingers. When you are fairly confident that he has your order straight, you say, ‘Yes, that’s all,’ and then he tells you how much you owe. I generally skip this part and look for a twenty dollar bill since it is a bit difficult to finger read two dollars and fiftyseven cents, especially with a Texas accent.”

Many Deaf people ignore the menu and speaker and simply drive up to the order window to deliver their order by speaking directly to staff, or handing a piece of paper with their desired choices to the window attendant. Even that is not without drawbacks. Jonathan O’Dell recounts how, several years ago, he was involved in a situation where someone’s deaf parents had done just that, and the ignorant hearing manager of the fast food franchise would have none of it and ordered the deaf seniors to move immediately. They refused, and the manager called the police. It was only after horrified national executives of the franchise had received a complaint from the deaf seniors’ daughter that Jonathan was asked to go and educate the franchise staff at this location about the communication needs of Deaf and late-deafened individuals.

This sort of moral stand is important. Had the deaf seniors simply decided to move, there would have been no lessons learned and no progress made. Because they knew their rights and refused to be treated as second-class citizens, they made change happen, unpleasant and frightening as it was with the police involved.

■ Parties

One way to handle a social gathering is to arrive early so that you can chat privately with your host and hostess before the other guests arrive. During the party, try to find a quiet spot where you can position the speaker to best advantage. Or, if possible, you may be able to go into a quiet room away from the noise of the main room. If you find an interesting person you’d love to talk to - which is one of the reasons people go to parties — but the noise and lighting level make this impossible, then by all means say as much and ask the person if they would be interested in continuing the conversation somewhere more amenable to someone with hearing loss.

■ Driving and Traveling

Traveling presents an interesting set of problems...although, just in case you were wondering, deaf drivers as a group have an impressive safety record.

- In the car: Conversing with a passenger while driving isn't really recommended. You need to concentrate on the road, and the tendency is to turn toward the speaker so you can speechread. This not only upsets passengers but also fellow motorists, since keeping your car straight when you're looking sideways isn't the easiest thing to master and is positively suicidal in Boston traffic. I've had good luck using an ALD in the car, but since that means my external microphones become inoperable, I sacrifice my ability to hear sirens and must ask my passenger to alert me to approaching emergency vehicles. The major American car manufacturers used to offer generous rebates on devices that warn of the approach of a siren. Turn signal audible/visual blinkers, wide angle rearview mirrors and overhead lights are practical, too. There are even portable audio loop installations specifically for cars! The easiest solution, of course, is to let the hearing person drive.
- Air travel: All of us know the story about the stewardess who gave a deaf passenger a card with Braille instructions. It usually isn't that bad. Until the airlines install monitors that tell travelers if flights are delayed or cancelled, the best approach is to arrive early and notify the ticket taker that you're deaf and that someone should personally deliver any announcements that come over the loudspeaker. Aboard the plane, remind the stewardess again. Air travel is one area where universal design would be a real benefit for everyone.
- Update: If you are Deaf or hard of hearing, federal law prohibits you from sitting in an Exit row, so be aware of that and notify the flight attendant if you find yourself in one. The reason for this is practical - in the event of a crash and evacuation, the circumstances will probably not be conducive to communication, so it makes sense for a person who is able to hear, see, and move independently to sit next to an emergency exit.
- Hotels and motels: Under the Americans with Disability Act (ADA) (see the second part of this chapter), places of public

accommodation are required to provide communication access to deaf and hard of hearing people. This means that you should be able to arrange for closed captioned television, visual smoke and fire alarms, TTYs, telephone amplifiers, alarm clocks, and door knock signalers. Call ahead to reserve the equipment, make sure it's there, and raise the dickens if it isn't. It's important for hotel management to know that this is not a trifling matter. Too often, people think that accessible is synonymous with wheelchair ramps. If there are conference rooms and meeting spaces, tell management about ALDs, CART, interpreters etc.

Jonathan O'Dell of the MCDHH CATTS Department has prepared an informative talk about "Traveling with Hearing Loss: A Basic Primer for Real and Wannabe Globetrotters." You can ask him to speak to your group.

Different advice applies if you are traveling domestically or overseas, and how you plan to travel: staying close to "civilization" or forging a trail through the wilderness. You'll need lots more preparation for the latter.

■ Before you leave

Needless to say, you should pack extra batteries for your hearing aids or cochlear implant and everything else that takes batteries. If you use rechargeable batteries, bring the charger. You'll want to bring any external microphones you normally carry and small ALDs such as vibrating watches, which are ideal because you need a watch anyhow, and this one will wake you without your needing to give some stranger a room key or lug along a big AC alarm with a bed shaker and power converter.

For domestic travel, the ADA (which we discuss later in the chapter) applies, so write in advance to the hotels where you'll be staying and ask for a room with the accommodations you need, mentioned above. Check with the sites you plan to visit to determine if they have ALDs, CART, interpreters, scripts or whatever you need. Of course, you'll need to check for cell phone/pager compatibility before you leave - most countries other than the US operate on GSM, not GPRS; check to see if your phone is GSM compatible and if international roaming is activated. When going overseas, you'll have to take electrical outlet adapter plugs with you, since few countries have the same plug configurations. If your gadgets are

rated at 110V only, you'll also need a converter that converts the more commonly used 220 - 240 Volts in Europe and elsewhere to the 110 Volts at which your device operates.

Assume that your luggage will be lost, so identify it inside and out and keep everything you need desperately in your carry-on bag. If you're really roughing it, you may want to pack everything in "dry bags" and sealed containers such as those used for kayaking, then place these bags in your luggage. You may want to take a roll-up solar charging panels (see www.brunton.com) that can recharge almost anything. And if you're going to be engaging in risky activities that absolutely demand some hearing ability, you'll want to pack old hearing aids or processors so that you won't destroy your expensive new equipment when you capsize or get caught in a monsoon.

■ Screening Precautions

You'll need a hip pack or pouch for vital items: passport, medications, tickets, wallet, etc. Stick it into your carry-on bag when you're screened, then take it out and keep it on wherever you go. Take literature about your implant to calm the baggage screeners in case they think you may be an "ear bomber." Recharge any gadgets you're taking beforehand, so you can demonstrate what they do if necessary.

■ Abroad

For overseas travel, be aware that there is no ADA in effect. "Be polite when asking for assistance or you won't receive any," cautions Jon. You'll want to make sure that the hotel will alert you in case of fire. You may wish to give a spare key to your room to a hearing group member if you're traveling as part of a group and are comfortable with the idea of this individual having access to your room. There are also gadgets available that mount on the door using Velcro and will trigger a vibrator under your pillow or bed when someone enters your room while you are sleeping, just as there are motion detectors that can be strategically placed to alert you to any presence in a specific area.

You're an ambassador

"The way you conduct yourself with a group will impact other travelers with hearing loss down the road," cautions O'Dell. If you're trav-

eling in the U.S., you may have to educate hotels about how to use their ADA equipment kits and you may have to insist quite firmly that tour groups not discriminate against you. You need to remind any travel entity you are dealing with, from airlines to hotels, from car rental agencies to group operators, that there are an estimated 28 million potential customers with hearing loss out there and that, like anyone else, we vote with our wallets. Obviously, you should not be patronizing a business that discriminates against you. Support those that do even if they cost a bit more or don't have the specific itinerary you may dream of. It's worth it in the end knowing you haven't implicitly supported discriminatory practices.

■ Churches and Meetings

Places of worship do not fall under ADA regulations, unless they are used for public meetings. But most churches and synagogues are very responsive to their congregation's needs. The point, after all, is for as many people as possible to participate in the service. This is one area where you can have an impact. You can teach the church about available assistive listening systems, perhaps help try them out. You may be able to persuade people to donate money to buy the systems or you might volunteer to distribute receivers at services, or check batteries periodically. MCDHH maintains a list of churches and synagogues that have interpreted services. If you're concerned about the accessibility of meetings, phone ahead and speak to the organizers. Many have no idea that there are such things as CART service, interpreters, or ALDs. So you can be an advocate in this type of situation as well.

For small meetings around a conference table, you should try a number of tactics:

- Ask for CART or CAN, or sit next to whoever is taking notes for the minutes and read over his or her shoulder.
- Ask for an interpreter/transliterater of your choice (oral, ASL, Signed English).
- Ask for a written agenda.
- You may be able to reconfigure seating arrangements. A U-shaped or circular table is usually best.
- Suggest that the chairperson use a whiteboard to write important points.

- Use an ALD if it can help you. Make sure that a communication protocol is firmly established and do not be afraid to raise your hand and interrupt when people are starting to break communication rules.
- Ask associates to speak one at a time and to face you.
- Ask the chairperson to repeat questions from the floor if it is not feasible for the microphone to be passed back or for the person to be asked to come to the front.

School

Many of the tactics listed above will also work in a classroom setting. If you benefit from an assistive listening device, the teacher can wear a microphone and carry a pocket-size transmitter in a pocket. CART, interpreters, and CAN are all possibilities. Some students have been successful asking their teachers for copies of the teaching curriculum. As we saw in Chapter 1, Annette Posell came to class super-prepared; while her fellow students were struggling to finish the required reading, she was reading every item on the reading list, required and suggested. Helen Fleming tells how her family bought her a small tape recorder and volunteered to transcribe tapes of lectures, only to discover that it was a great deal harder than they expected. Today, CART service is commonly used by late deafened and severely hard of hearing students in schools and colleges.

What are your rights under the ADA?

The Americans with Disabilities Act was signed into law on July 26, 1990. It protects people with disabilities, including those who are deaf and hard of hearing, from discrimination in employment, access to state and local government services, places of public accommodation, telecommunications and transportation. Employers and business owners are required to make “reasonable accommodations” unless that creates an “undue financial burden or fundamentally alters the nature of the program or service provided.” The ADA also amended the Communications Act of 1934 to require that each state provide 24 hour per day Telephone Relay Service for consumers with hearing loss and speech impairments.

You can find information and guidelines about filing a complaint at www.usdoj.gov/crt/ada/t3compfm.htm (for Title 3 complaints) and www.ada.gov/t2cmpfrm.htm (form for Title 2 complaints).

So much has been written about the law that it is not productive to reinvent the wheel here. If you need further information, contact MCDHH's Communication Access, Training and Technology Services department. The MCDHH website also has information about the ADA and how it pertains to hearing loss (www.mass.gov/mcdhh). —

The ADA is not the only law protecting the rights of disabled individuals. Section 504 of the Rehabilitation Act of 1973 states that “No otherwise qualified handicapped individual in the United States... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.”

10. EMERGENCY PREPAREDNESS

Anyone who lived through 9/11 and watched the aftermath of Katrina has to worry about how to deal with an emergency. The hard of hearing and deaf populations were particularly hard hit for a number of reasons: Closed captioning was dropped from television broadcasts in favor of rolling headlines at the bottom of the screen, so that people with hearing loss could not keep up with the latest breaking news, and were instead left reading the re-hashed headlines over and over again. Similarly, the telecommunications infrastructure faltered badly. Landline telephones were overloaded. Cell phones didn't function near Ground Zero or in New Orleans. During Katrina, shelters had few sign language interpreters and CART providers. As cochlear implant user Alison Anderson wrote in her blog, "The Bionic Sound Project," "One of the worst things about being deaf is that if there is something going on, you're usually the last person to know about it. 9/11 was a perfect example of mass chaos and no information of what was happening other than the pictures."

Nor has the situation been remedied. According to the Disability Policy Consortium (DPC), in July 2006, "a new director of emergency planning in Plymouth, MA, found the only substantive example of disability-readiness was a list of 100 people with disabilities in his community of 59,000."

"America's current public warning and emergency communication systems get a failing grade from deaf, hard of hearing, late-deafened and deaf-blind individuals," concludes a report published at the end of 2004 by the Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN) and the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons (NVRC). "Without effective communication systems, deaf and hard of hearing individuals do not know that there is an emergency, cannot learn what steps must be taken to protect themselves and others, and have no access to critical resources in the aftermath of an emergency."

■ Levels of preparation

1. Planning: Deaf, late-deafened, hard of hearing and deaf/blind individuals must be actively involved in disaster planning at the local level. It is far easier, less expensive, and more effective to establish plans that accommodate individuals with hearing

loss and other disabilities from the outset than it is to re-write existing plans mid-stream.

2. Infrastructure: We need to build redundant notification systems at federal, state, and local levels. It is not enough to do so only at the highest level of government because many disasters are by nature local and do not receive broad nationwide exposure, certainly not with the level of detail someone living in or near the affected community may wish to receive. Everyone, from the FCC to television manufacturers, broadcasters to content programmers, has to be involved in this effort. Duplicate systems must be in place to insure successful notification, even if one system is incapacitated. Community planners must make shelters fully accessible whenever feasible, plan transportation options to include persons with disabilities, and be able to contact residents using communication methods of the resident's choice, which is usually dictated by the degree of their hearing loss. As the DPC commented, federal and state governments must develop and publicize best methods for handling certain problems so that, for example, "every community does not have to invent the best way to decontaminate a person in a power wheelchair."
3. Distribution of communications devices: There must be an effort to equip people with hearing loss with devices that can alert them to an emergency, such as NOAA weather radios with audible, texting, and tactile alerting options, portable televisions, alphanumeric pagers, and two-way text messaging devices. Although no single device will work in every situation, the more options for communication people with hearing loss have, the better. Some of these devices should be battery operated - using conventional, readily available off-the-shelf alkaline batteries, in case there is a power outage. Too many manufacturers design their units so they will only run on proprietary batteries that users cannot replace themselves easily, and which render the devices useless if they cannot be recharged during a multi-day power outage.
4. Buddy system: As low-tech as it may be, people who are deaf and hard of hearing should make plans for a "buddy" at home and work, preferably a hearing person who can tell them what is going on by writing messages, etc. However, this should not in any way lessen the individual's responsibility to devise a

complete action plan for the family, just in case the buddy is unavailable. Every family member should understand the plan and be able to execute it without the need to communicate.

5. Personal: Each citizen has a responsibility to know the location of emergency shelters, emergency exit routes, emergency telephone numbers, etc. If you need special assistance in an emergency, you should inform your local emergency personnel. For example, if you cannot use a voice telephone, your local government agencies in charge of notifying residents should know and make plans to call you via TTY or relay. Don't assume that they have any particular services. Contact them now to discuss your needs.

Personal Preparations

It is necessary to know the location of your community shelter and check to see if it has the necessary accommodations for your needs. Where is the nearest shelter to your work or school? Does it have a TTY? Is there any plan of action that calls for interpreters and CART providers to be contacted as a matter of course during any emergency, to facilitate communicate with you? Is there a location where you can bring your pets?

You and your family should discuss what you should do in an emergency before one occurs. Optimally, you should make different plans depending on the nature of the emergency or disaster - a nuclear device explosion will necessitate a vastly different response from a pandemic flu outbreak. You should plan a meeting point at a shelter, landmark, or in another town. Each of you should have emergency numbers that you always carry, in hardcopy or on a handheld device, perhaps on a USB flash drive. You should all have the name and contact information for relatives or friends who live at sufficient distance that they will probably not be affected by a local disaster. If you can't check in with each other, check in with your support people. Make sure that these people have full contact information for you as well. If you can afford it, purchase alternate devices for communications and receiving text messages and subscribe to a service that will alert you to disasters.

You will want to keep an up-to-date list of the medications you take, the dosage, and refill and expiration dates. If you need periodic medical checkups (for example, blood tests) write that down, too, and make note of their frequency. List any medical equipment you

need, such as a CPAP machine or hearing aids. You should have an emergency ID bracelet or necklace if you have allergies or health conditions. You should jot down model numbers with contact information in case you have to reach the vendor or manufacturer, and any supplies that are needed for it. Are there any options to operate them from batteries? You also want to include the names and contact information for any health care providers. If you cannot reach them, ask for alternatives in case of emergency. Finally, you should make copies of birth certificates, licenses, social security cards, insurance information for health, home, and car, prescriptions, passports, and immunization information. These, too, can be digitized and stored on password-encrypted USB flash drives, so you don't stumble through the aftermath of a disaster with a wheelbarrow full of paperwork.

Pack an emergency bag (your Go Bag) and keep it near the door. It should contain:

- The documents listed above, as well as vaccination information and veterinary contact information for your pets and service animals. This is another candidate for storage on a flash drive.
- Food, including any special diets for your family and nourishment for your pets and hearing dog.
- A flashlight and extra batteries. An LED light is preferable to a regular incandescent because of the much longer run time and the more hardy nature of LED lights. Though pricey, lithium batteries have a 10-year shelf life and are far less susceptible to cold than regular alkaline batteries.
- A supply of bottled water and easily stored food (such as granola bars and nuts) at home and packed in the trunk of your car - but be aware that during hot summer days, you will not want to leave any emergency kit with medications or heat-sensitive food in a broiling car trunk.
- Extra batteries for your hearing aids and cochlear implants, packed in a waterproof bag or canister
- Recharger and AC adapters if any of your devices take rechargeable batteries; also, a power inverter that will allow you to use any car's cigarette lighter socket to power electrical devices.

- Solar battery chargers, if you're really into end-of-the-world scenarios or adventure-style travel, in which case you may already have them.
- Medications, toothbrush, hygiene and sanitary products, sun-screen, insect repellent, antibiotic hand sterilizer
- Supplies for cleaning earmolds and other equipment
- A change of clothing, according to the season

In addition, you should have a bag in your car with a similar collection, including a blanket, jumper cables, etc. Always keep a good supply of gas in the tank. You don't want to be stuck waiting in line at a gas station in a time of disaster.

Check the bag every six months to replenish batteries, food, and medications. If you have a computer, subscribe to the CEPIN (Community Emergency Preparedness Information Network) newsletter and keep abreast of the latest developments and tips.

Pray that you never have to deal with an emergency or disaster.

11. FINAL WORDS

■ Further Reading

There are a number of books on deafness that you may find interesting. The following sampling includes several written by late-deafened authors, as well as a handful of more generalized titles.

General Books

John M. Burkey, **Baby Boomers and Hearing Loss: A Guide to Prevention and Care** (Rutgers Univ. Press, 2006)

Richard Carmen, ed. **The Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Healing**, (Auricle Ink Publishers, 1998)

Susan V. Rezen, **Coping With Hearing Loss, Revised Updated ed.** (Barricade Books, Inc., 2000)

Carol Turkington and Allen E. Sussman, ed. **The Encyclopedia of Deafness and Hearing Disorders, 2nd edition** (Facts on File, 2000)

David Vernick and Constance Grzelka, **The Hearing Loss Handbook** (Consumer Reports Books, 1993)

Books By and About People with Hearing Loss

Beverly Biderman, **Wired for Sound: A Journey Into Hearing** (Trifolium Books, 1998)

Michael Chorost, **Rebuilt: My Journey Back to the Hearing World** (HC edition: Souvenir Press ; Pb edition: Mariner Books, 2006)

Mark Drolsbaugh, ed. **On The Fence: The Hidden World of the Hard of Hearing** (Handwave Publications, 2007)

Marcia B. Dugan, **Living with Hearing Loss**, (Gallaudet Univ. Press, 2003)

Stephanie D. Halvorson, **Threading the Snail: My Journey Through Deafness** (Tate Publishing & Enterprises, 2006)

- Michael A. Harvey, **Listen With the Heart: Relationships and Hearing Loss** (Dawnsign Press, 2001)
- Michael A. Harvey, **Odyssey of Hearing Loss: Tales of Triumph** (Dawnsign Press, 2004)
- Anne Pope, **Hear: Solutions, Skills, and Sources for Hard of Hearing People**, Dorling Kindersley in collaboration with SHHH, 1997
- Arlene Romoff, **Hear Again: Back to Life with a Cochlear Implant** (League for the Hard of Hearing, 1999)
- Bena Shuster, **Life After Deafness; A Resource Book for Late-Deafened Adults** (Canadian Hard of Hearing Assoc., 1995)
- Barbara Stenross, **Missed Connections** (Temple Univ. Press, 1999)
- Elaine Suss, **When the Hearing Gets Hard** (Plenum Press, 1994)
- Kay Thomsett and Eve Nickerson, **Missing Words; The Family Handbook of Adult Hearing Loss** (Gallaudet Univ. Press, 1993)
- Bonnie Tucker, **Cochlear Implants: A Handbook** (McFarland & Co., 1998)
- Dora Tingelstad Weber, **Journey Out of Silence** (Beaver's Pond Press, 1998)
- Dora Tingelstad Weber, **I Danced: A Cochlear Implant Odyssey** (Beaver's Pond Press, 2004)
- David Wright, **A Quiet World: Living with Hearing Loss** (Yale Univ. Press, 2000)

■ Periodicals

- **ALDA News.** Quarterly. Free with membership: ALDA Inc., 8038 MacIntosh Lane, Rockford, IL 61107; www.alda.org
- **Hearing Health Magazine.** Deafness Research Foundation, M Street NW, Washington, DC 20007. (866) 454-3924 (Voice); (888)435-6104 (TTY); (202) 338-8182 (Fax); www.drf.org

- **Hearing Loss Magazine.** Bimonthly. Subscriptions available through membership only. Hearing Loss Association of America, 7910 Woodmont Ave., Suite 1200, Bethesda, MD 20814; www.hearingloss.org
- **The Mike.** Free subscription with membership in Minuteman Implant Club, Inc. Larry Orloff, President, 209 Rolling Ridge Road, Amherst, MA 01002. Phone:(413) 549-4108 E-Mail: orloff@comcast.net; www.cisupport.org
- The Alexander Graham Bell Association for the Deaf and Hard of Hearing publishes the **Volta Review**, a research publication. AG Bell also publishes the Volta Voices, a magazine for families. The Alexander Graham Bell Association for the Deaf and Hard of Hearing, 3417 Volta Place, NW, Washington, DC 20007; www.agbell.org

In Conclusion...

You've read the guide. It's now time to see if you can adopt any of the suggestions or want to pursue some of them in-depth, time to discover what coincides best with your needs and personal style, what works for you. I hope I've been able to give you a groundwork on which you can build. Be adventurous. Have fun. Above all, maintain your sense of humor. The journey is just beginning.

If you have any suggestions, questions, or comments, I'd like to hear from you. I can be reached at:

karen@karenrockow.com

Or contact:

**The Massachusetts Commission
for the Deaf and Hard of Hearing
150 Mt. Vernon Street, Fifth Floor
Dorchester, MA 02125.**

For updated information on available resources please contact MCDHH for a copy of the most recent **Statewide Resource Directory**

APPENDIX: REFERENCES

Chapter 2: Where to Turn for Help

Support Groups

- Acoustic Neuroma Association (ANA)
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
770/205-8211 (v)
770/205-0239 or 877/202-0239 (fax)
www.anausa.org
Publication: quarterly newsletter
- ALDA-Boston (serves members across the state)
P.O. Box 600622
Newtonville, MA 02460
www.aldaboston.org
- ALDA, Inc (national office)
8038 MacIntosh Lane
Rockford, IL 61107
866/402-2532 (v/tty)
www.alda.org
- Alexander Graham Bell Association for the Deaf and
Hard of Hearing
Massachusetts Chapter (AG Bell, MA Chapter)
P.O. Box 220
Topsfield, MA 01983
978/312-1200
www.massagbell.org

- Alexander Graham Bell Association for the Deaf and Hard of Hearing
3417 Volta Place, NW
Washington, DC 20007
202/337-5220 (v)
202/337-5221 (tty)
202/337-8314 (fax)
info@agbell.org
www.agbell.org
- Hearing Loss Association of Greater Boston
Laura Meier
Boston MA
Phone 617/479-1106 (tty)
Lmeier8339@yahoo.com
- Hearing Loss Association, North of Boston Chapter
Helen Fleming
Lynn MA
781/592-6936 (v)
nellie.may@verizon.net
- Hearing Loss Association, Cape Cod Chapter
Ellen Taylor
East Bridgewater MA
508/378-1132 (v)
ellen@shhhcapecod.org
www.hearingloss.org/chapters/chapterlist.asp?state=MA
- Hearing Loss Association of America (HLAA)
7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
301/657-2248 (v/tty)
301/913-9413 (fax)
www.hearingloss.org

- Massachusetts State Association of the Deaf (MSAD)
220 Main Street
Malden, MA 02148
781/388-9114 (v)
781/388-9115 (tty)
781/388-9015 (fax)
781/388-9116 (Sorenson VP)
70.90.107.197 (vp)
www.msad.org
- Minuteman Implant Club (MIC)
209 Rolling Ridge Road
Amherst, MA 01002
413/549-4108
www.cisupport.org
- The NF2 Crew
18418 North 104th Avenue
Sun City, AZ 85373
623/322-3168
www.nf2crew.org

Organizations Offering Support Services

- Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)
attn: Case Management Services
150 Mt. Vernon Street, Suite 550,
Dorchester, MA 02125
617/740-1600 (v)
617/740-1700 (tty)
617/740-1800 (fax)
Toll free:
800/882-1155 (v)
800/530-7570 (tty)
Videophone: Dial 617-265-8447
or use the following IP address: 70.22.152.162
(offices also in Springfield, Worcester and Plymouth)
www.mass.gov/mcdhh

- DHILS (Deaf and Hard of Hearing Independent Living Services/Programs)
Contact MCDHH for the current DHILS list or visit the MCDHH office
- Northeastern University Speech-Language and Hearing Center
Boston Guild for the Hard of Hearing
Behrakis Health Sciences Center
Room 503
30 Leon Street
Boston, MA
617/373-2492 (v)
617/373-8927 (tty)
617/373-8756 (fax)
www.slpa.neu.edu/guild/index.html
- The Hearing Rehabilitation Foundation
35 Medford St.
Somerville, MA 02143
617/628-4537
www.hearf.org

Computer Forums and Support Groups

- Beyond Hearing
Steve Barber maintains the Beyond Hearing website at www.geocities.com/Heartland/Prairie/4727/bhnew.htm
You can subscribe to Beyond Hearing there.
- Better Hearing News (bhNEWS)
You can join bhNEWS, through the Yahoo Groups at groups.yahoo.com/
and sign up bhNEWS-subscribe@yahoogroups.com
- SayWhatClub
To join SWC, contact info@saywhatclub.com. The club's website, www.saywhatclub.com, contains copies of their newsletters, essays, and other items of interest.

- HearingExchange
www.hearingexchange.com
- Hearing Loss Web
5663 Balboa Ave. #357
San Diego, CA 92111
858/278-9630 (v/tty)
www.hearinglossweb.com

To subscribe to HOH-LD-News, email
HOH-LD-News-subscribe@yahoogroups.com.
Yahoogroups will respond with a subscription email.

- Hearing Mojo
www.hearingmojo.com

Mental Health Counseling and Emergency Intervention

- For referral to specialized mental health therapists for the deaf: Contact MCDHH
- For referral to emergency intervention programs:
Contact DHILS programs across the state
Contact MCDHH

Financial Assistance

- Massachusetts Assistive Technology in Consumer's Hands (MATCH)
Massachusetts Rehabilitation Commission
27 Wormwood Street, Suite 600
Boston, MA 02110
Program Director: Kobena Bonney 1-866-682-9955
617-204-3851 (v)
617-204-3851 (tty)
617/204-3887 (fax)
www.mass.gov/mrc

MCDHH Assistive Technology Fund Program

- Marcy Macone, Benefits Specialist
Case Management Department, MCDHH
150 Mt. Vernon Street, Suite 550
Boston, MA 02155
617-740-1653 (v)
617-740-1753 (tty)

Social Security

- SSI, SSDI, and Health Plans
www.massresources.org/

CommonHealth

- MassHealth Customer Service Center
800/841-2900 (v)
800/497-4648 (tty)
www.mass.gov/masshealth

Massachusetts Division of Medical Assistance (DMA)

- Medicaid Program
600 Washington Street
Boston, MA 02111
888/665-9993 (v)
888/665-9997 (tty)
www.mass.gov/dma

Massachusetts Rehabilitation Commission

- Mass. Rehabilitation Commission (MRC) has many offices across the state.
To find your MRC Office and/or Rehabilitation Counselor for the Deaf, call information. (www.mass.gov/mrc)

U.S. Department of Veterans Affairs (formerly Veterans Administration)

- Health care benefits and services from the Veterans Health Administration www.va.gov/health

Hear Now (HN)

- Hear Now
6700 Washington Avenue South
Eden Prairie, MN 55344
800/648-HEAR (4327) (v)
612/828-6946
www.sotheworldmayhear.org/hearnow/

Services for Senior Citizens**Deaf Senior Centers**

- St. Andrews Church for the Deaf
c/o St. Paul's Church
39 East Central St.
Natick, MA 01760-5880
508/655-5880
standrewsdeaf@aol.com
- North Shore Deaf Senior Citizens Center
New England Homes for the Deaf
154 Water Street
Danvers, MA 01923
978/774-0445 (v/tty)
Thursdays: 9:00 a.m. - 3:00 p.m.
- South Shore Deaf Senior Citizens Center
Atlantic Neighborhood Center
11 Hollis Street
Quincy, MA 02171
617/773-9280 (v/tty)
Mondays: 10:00 a.m.-3:00 p.m.
- Central Mass Deaf Senior Center
St. Matthew's Parish House
695 Southbridge Street
Worcester, MA 01610
508/753-2526 (v/tty)
Thursdays: 10:00 a.m. - 3:00 PM

- Merrimack Valley Deaf Senior Citizens Center
South Congregational Church
198 South Broadway
Lawrence, MA 01843
978/683-9163 (v/tty)
(Mon. 9:00 a.m.-12:00 p.m.)
Tuesdays: 9:00 a.m.-2:00 p.m. (except 2nd week of the month, Monday instead)

New England Home for the Deaf (NEHD)

- New England Home for the Deaf
154 Water St.
Danvers, MA 01923
508/774-0445 (v/tty)

Gallaudet Univ. Elderhostel Program for Deaf Senior Citizens

- Gallaudet University
University Conference Management
800 Florida Ave., NE
Washington, DC 20002
202/651-6000 (v/tty)
202/651-6107 (fax)

Chapter 3: Communication Options

Speechreading

- Boston Guild for the Hard of Hearing at Northeastern Univ.
Northeastern Univ. Speech-Language and Hearing Center
503 Behrakis Health Sciences Center
30 Leon St.
Boston, MA 02115
617/372-1189
www.slpa.neu.edu/guild/index.html

- University of Massachusetts/Amherst
Center for Language, Speech and Hearing
715 North Pleasant St.
Amherst, MA 01003
413/545-2565
413/545-0803
Umass.edu/SPHHS/ComDis
- Worcester State College
Speech, Language and Hearing Clinic
486 Chandler St.
Worcester, MA 01602
508/929-8567
Worcester.edu/Academius/comm_disorders

Speechreading Software

- "Seeing and Hearing Speech," 2001
Sensimetrics Corp.
48 Grove St., Suite 305
Somerville, MA 02144
617/625-0600; 617/625-6612 (fax)
www.seeingspeech.com

You can select any of eleven different speakers, male and female, on CD ROM to practice speechreading. Inserts background noise and music for realism. Runs under MS Windows 98 and higher, or Macintosh OS 8.1 or higher. Requires 35 MB or more hard drive storage, minimum of 64 MB RAM, 12x or faster CD-ROM drive.

- "Speechreading Challenges; A Multimedia Experience in Learning Speechreading Skills", 1999
CD-ROM requires PC with Windows 95/98 or Macintosh with MacOS 7.5.3 or higher, at least 200 Mhz processor, 32 MB RAM, 4x CD-ROM, Quicktime 3.0 or higher.

- "Read My Lips"
6-lesson home study course in VHS or DVD format

Many of these CD-ROMs and videos are available from vendors such as Harris Communications. See Chapter 11 for sources.

American Sign Language

- American Sign Language Class List
MCDHH CATTs Department
617/740-1600 (v)
616/740-1700 (tty)
www.mass.gov/mcdhh
- **A Basic Course in American Sign Language** by Tom Humphries, Carol Padden & Terrence O'Rourke (T.J. Publishers, 1994); also available in Spanish and on video-tape. Humphries and Padden have also written another book, **Learning American Sign Language**, also available with a video.
- **American Sign Language; a Comprehensive Dictionary** by Martin Sternberg (Harper & Row, 1981); also available in paperback condensed form and as a CD ROM
- **Books for Learning Sign Language** (NCID) Describes available books
- **Everyone Here Spoke Sign Language; Hereditary Deafness on Martha's Vineyard** by Nora Groce (Harvard Univ. Press, 1985)
- Learning Sign Language: Audio Visual/Computer Programs (NCID) Lists videotapes and computer programs for learning sign language

- **Signing Naturally:** a very popular curriculum; video and text Bravo ASL! Curriculum, Sign Enhancers. A well-regarded beginning ASL videocourse, now available online, in streaming video at the Described and Captioned Media Program (DCMP). Go to www.cfv.org, sign up for a password, and search the catalog for "Beginning ASL Videocourse." Many books on ASL are available, even an "Idiot's Guide," which contains a number of errors, I'm told. Check your booksellers, libraries, and catalogs listed in Chapter 11.

Fingerspelling

- "Interactive Sign Language: Fingerspelling & Numbers," (Palatine, 1992) Computer program. Several shareware programs are also available.
- **Fingerspelling in American Sign Language** by Brenda E. Cartwright and Suellen J. Bahleda (2002)

Signed English

- **The Signed English Starter** by Harry Bornstein and Karen Saulnier (Gallaudet); these authors have written a number of other books about Signed English and, with Lillian Hamilton, have edited a comprehensive dictionary of Signed English.

Cued Speech

- National Cued Speech Association
23970 Hermitage Road
Cleveland, OH 44122
800/459-3529 (v/tty)
www.cuedspeech.org
- NCSA Information Services/Bookstore
CuedSpDisc@aol.com

- New England Cued Speech Services
web7.mit.edu/CuedSpeech

Chapter 4: Communication Skills

- Contact MCDHH
Speak to your audiologist for suggestions.
Look into some of the aural rehabilitation programs at the Boston Guild at Northeastern University and the Hearing Rehabilitation Foundation in Somerville.

Chapter 5: Hearing Aids and Cochlear Implants

Hearing Aids

- Contact MCDHH
- “Help with Hearing Aids - A Three-Part Series”: Report 1: “Preparing for and Getting the Most Out of a Visit to a Hearing Aid Dispenser”, and Report 2: “Selecting and Purchasing a Hearing Aid”, and Report 3: “Troubleshooting Your Hearing Aid.” (Available in the Reports section from the HLAA Bookstore at www.hearingloss.org)
- **The Consumer’s Guide to Hearing Aids**, The Wilson Group, 2006. (Available from HLAA Bookstore at www.hearingloss.org)
- **A Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Hearing** edited by Richard Carmen. Auricle Ink Publishers, 1998. (Available from www.hearing-problems.com)
- **The Hearing Aid Handbook** by Donna Wayner. Gallaudet Univ. Press, 1990
- **Overcoming Hearing Aid Fears: The Road to Better Hearing** by John M. Burkey, Rutgers University Press, 2003.

Organizations

- American Academy of Audiology
11730 Plaza America Drive, Suite 300
Reston, VA 20190
800/AAA-2336, 703/790-8466 (v)
703/790-8631 (fax)
www.audiology.org
- American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, Maryland 20852
www.asha.org
- Hearing Industries Association
515 King Street, Suite 420
Alexandria, VA 22314
703/684-5744 (v)
703/684-6048 (fax)
www.hearing.org

Hearing Aid Manufacturers

- GN Resound
www.gnresound.com
- Oticon
www.oticon.com
- Phonak
www.phonak.com
- Siemens
www.siemens.com
- Starkey
www.starkey.com

- Vivatone
www.vivatone.com
- Unitron
www.unitronhearing.us/
- Widex
www.widex.com

Online Resources

- "How to Maximize Your Success with Hearing Aids," and "What you need to know about hearing aids," Hearing Planet, 2006. Hearing Planet is a network of clinics that sell hearing aids. www.hearingplanet.com
- "Your Guide to Better Hearing" and "Your Guide to Hearing Aids" can be downloaded from www.betterhearing.org/request_information.cfm
- "When Hearing Grows Difficult" from AARP at www.aarp.org/money/wise_consumer/smartshopping/a2002-10-03-WiseConsumerDifficultHearing.html
- "Hearing Aids," www.hearinglossweb.com/res/ha/ha.htm
- "Hearing Aids" and "Hearing Loss and Older Adults" from the National Institute on Deafness and Other Communication Disorders, www.nidcd.nih.gov
- "T-Coils: Beyond the Telephone" by Douglas L. Beck and "T-Coils: Getting The Most out of Your Hearing Aid" by Nancy L. Aarts, www.audiologyonline.com

Vibrotactile Aids

- Audiological Engineering Corporation of Somerville, MA has gone out of business, leaving no manufacturer of tactile aids for people with hearing loss.

- The Hearing Rehabilitation Foundation
35 Medford St.
Somerville, MA 02143
617/628-4537 (v)
HearF@aol.com

www.hearf.org

HRF President Geoff Plant is a leading authority on tactile aids.

Cochlear Implants

Cochlear Implant Manufacturers

- Advanced Bionics
12740 San Fernando Rd.
Sylmar, CA 91342
800/678-2575 (tel)
661/362-1400 (tel)
800/678-3575 (tty)
661/362-1500 (fax)
Email: info@advancedbionics.com
www.advancedbionics.com

The Bionic Ear Association is a network of Advanced Bionics consumers (To join, go to www.bionicear.com, click the "Consumers" tab and then select "BEA - Your Support Network")

- Cochlear Americas
400 Inverness Parkway Suite 400
Englewood, CO 80112
800/523-5798
303/790-9010 (tel)
303/792-9025 (fax)
www.cochlear.com

Cochlear's consumer group is the Nucleus Forum. (To join, go to www.cochlearamericas.com/Community/26.asp)

- Med-El Corporation
2222 East Highway 54,
Beta Building Suite 180
Durham, North Carolina 27713
888/633-3524 (v)
1-919/484-9229 (fax)
www.medel.com/ENG/US/

Med-El's Hearing Companions program lets CI candidates contact Med-El CI recipients and parents of Implanted children. You can join at www.hearingcompanions.com/

Support Group

- Minuteman Cochlear Implant Club:
Contact: Larry Orloff
209 Rolling Ridge Road
Amherst, MA 01002
413/549-4108
www.cisupport.org

Books:

- **Better Communication and Cochlear Implants: A User's Guide** by Donna S. Wayner, Hear Again Inc., 1998
- **Bridge to Sound With a 'Bionic' Ear**, Cynthia Farley, ed., Periscope Press, 2002
- **Cochlear Implants**, Susan B. Waltzman, Ph.D. and Noel Cohen, eds., Thieme Medical Publishers, 2006 [Reference]
- **Cochlear Implants: A Handbook**, by Bonnie Poitras Tucker, McFarland & Co., 1998

- **Cochlear Implants: A Practical Guide** by Huw Cooper and Louise Craddock, Wiley, 2nd ed. 2006 [Reference]
- **Hear Again: Back to Life with a Cochlear Implant**, by Arlene Romoff, League for the Hard of Hearing, 1999
- **I Danced: A Cochlear Implant Odyssey** by Dora Tingelstad Weber, Beaver's Pond Press, 2004
- **Rebuilt: How Becoming Part Computer Made Me More Human** by Michael Chorost, Houghton Mifflin, 2005. See also www.michaelchorost.com
- **Wired for Sound: A Journey into Hearing**, Beverly Biderman, Trifolium Books, Inc., 1998

Online Sources:

- The Beyond Hearing, and bhNEWS and SayWhatClub listservs (see section above on Computer Groups in Chapter 2 about online groups) often has have messages from people who have or are considering implants. Many people have posted "diaries" recounting their experiences after being "turned on."
- CI List: an Internet discussion group dealing specifically with cochlear implants. To subscribe, send a message to: CI@yorku.ca and in the text put "subscribe ci firstname lastname" (without quotes and using your real name). Do not put anything in the subject line.
- CIHear (To join the listserv, go to groups.yahoo.com/group/CIHear; the website is at: www.cihear.com)
- Neil Bauman's website has lots of information on cochlear implants. hearinglosshelp.com/weblog/?cat=18:

- This listserv chronicles difficulties people have had with cochlear implants. groups.yahoo.com/group/ProblemCI/
- "Cochlear Implant Information & Resources," www.listen-up.org/implant.htm
- "Cochlear Implants," Baylor College of Medicine, good introduction, www.bcm.edu/oto/jsolab/cochlear_implants/cochlear_implant.htm
- Interview with musician John Redden, an implant user, www.healthyhearing.com/library/interview_content.asp?interview_id=159
- "Introduction to cochlear implants" by Philipos C. Loizou, www.utdallas.edu/~loizou/cimplants/tutorial/tutorial.htm
- "Journey into Silence and Back" by viola student Wendy Cheng, one of the first online diaries of a cochlear implantee (1996), www.geocities.com/pstauffer/wendy/silence.htm
also see: www.aamhl.org/bios/teachingwendy.htm by her viola teacher

Blogs:

- BEEN COCHLEARIZED!
cochlearized.blogspot.com/search?q=cochlear
- The Bionic Sound Project: This Girl's Journey to Sound
bionically.wordpress.com
- Hear Again
hearagain.blogspot.com/
- Confessions of a Cochlear Implantee
bionicgal.blogspot.com/

- COCHBLA
cochbla.blogspot.com/
- CI HEAR
www.cihear.com/stories.html
- Hearing Loss Help on Cochlear Implants
hearinglosshelp.com/weblog/?cat=18

Videos:

- "Cochlear Implants: Covering the Basics," DawnSignPress, VHS 1995
- "Hear and Now," Vermilion Pictures. 2007, www.vermilionpictures.com Shown at Sundance Film Festival. Will be shown on HBO in 2008.
- "NOVA: Mystery of the Senses - Hearing," WGBH Boston, 2007.(10 min on CIs - showing Michelle Smithdas)
- "Sound & Fury," New Video Group, Inc, 2000 (VHS); 2002 (DVD).
- "Sound & Fury: Six Years Later," 2006. contact Josh Aronson at: Aronsonfilms@aol.com
aronsonfilms.com/contact_us.html

Auditory Brainstem Implants

- Cochlear Corp. (address in Cochlear Implant section above)
- House Ear Institute (where initial trials were held):
www.hei.org
- NYU Dept. of Neurosurgery
www.med.nyu.edu/neurosurgery

- “Different Kinds of Cochlear Implants: Auditory, Penetrating and Hybrid” by Mark Ross, Ph.D., www.healthy-hearing.com/library/article_content.asp?article_id=727, reprinted from Hearing Loss Magazine (May/June, 2006)

Chapter 6: Assistive Listening Devices and Systems

Assistive Listening Devices and Systems

- “Assistive Listening Devices - Aid for Hard of Hearing People,” by Jamie Berke
deafness.about.com/cs/aldis/a/assistivelisten.htm
- Do-It-Yourself Listening and Signaling Devices for People with Hearing Impairment by William Paschell, 1988, rev. 1991. Long out of print, this 85-page manual is available in pdf format at the Beyond Hearing website, by permission of the author:
www.geocities.com/Heartland/Prairie/4727/bhframe.htm. Click on Articles at the left, scroll down the list, and click on the manual.
- “How to Install an Audio Loop” by George DeVilbiss.
www.geocities.com/Heartland/Prairie/4727/bbhloop.htm?200715

Alerting Devices and Signaling Systems

- “Assistive Listening and Alerting Devices” (Quiet Corner SHHH, Inc.) qcshhh.tripod.com/id40.html
- “Assistive Technology”
www.asha.org/public/hearing/treatment/assist_tech.htm

Hearing or Signal Dogs

- **Chelsea; A Signal Dog** by Paul Ogden (Little, Brown and Co.) 1992
- **Lend Me an Ear: The Temperament, Selection and Training of the Hearing Ear Dog** by Martha Hoffman, Doral Publishing, 1999
- **Service Dogs** by Linda Tagliaferro and Meish Goldish, Bearport Publishing, 2007
- **Sound Friendships: The Story of Willa and her Hearing Ear Dog** by Elizabeth Yates, BJU Press, 1992
- Teamwork Training Manuals and Videos from Top Dog, an Arizona organization dedicated to teaching people with physical disabilities how to train their own service dogs. www.topdogusa.org/
- **Working Like Dogs, the Service Dog Guidebook** by Marcie Davis and Melissa Bunnell, Alpine Publications, 2007

Videos

- "Clicker Train Your Own Assistance Dog" by Barbara Handelman, 2004
- "Listen Up!" DVD by Martha Hoffman, Tawzer Dog Videos, 2002
- "Partners for Life: A Service Dog's Tale," Univ. of Arizona College of Agriculture and Life Sciences Diversity Committee, 1999. Introduces businesses to service dogs. ag.arizona.edu/agdiv/servicedog/

Well-Known Hearing Service Dog Organizations:

- Canine Companions For Independence
P.O. Box 446
2965 Dutton Avenue
Santa Rosa, CA 95402-0446
707/577-1700 (v)
707/577-1756 (tty)
707/577-1711 (fax)
info@caninecompanions.org
www.caninecompanions.org
- Dogs For The Deaf, Inc.
Robin Dickson
10175 Wheeler Road
Central Point, OR 97502
541/826-9220 (v/tty)
541/826-6696 (fax)
info@dogsforthedeaf.org
www.dogsforthedeaf.org
- Paws With A Cause
Michael Sapp
4646 South Division
Wayland, MI 49348
616/877-7297 (v)
800/253-7297 (tty)
616/877-7297 (tty)
616/877-0248 (fax)
paws@pawswithacause.org
www.pawswithacause.org/

Hearing Service Dog Organizations Serving Massachusetts:

- My Wonderful Dog
Elsa Larsen
PO Box 11371
Portland, ME 04104

207/780-9792 (v)
elarsen@wonderfuldogs.org
www.wonderfuldogs.org

- Dogs for Deaf and Disabled Americans (NEADS.)
Sheila O'Brien
P.O. Box 213
West Boylston, MA 01583
978/422-9064 (v/tty)
978/422-3255 (fax)
info@neads.org
www.neads.org
- Service Dog Project, Inc.
Carlene White
37 Boxford Road
Ipswich, MA 019383
978/356-0666 (v)
animalep@aol.com

Yahoo Support Groups for Hearing Service Dog Owners:

- Assistance Dogs
groups.yahoo.com/group/assistance-dogs/
- Golden Paw Assistance Dog Club
groups.yahoo.com/group/Golden_Paw_ADC/
- Hearing Dog Teams
groups.yahoo.com/group/hearingdogteams/
- Service Dogs
groups.yahoo.com/group/Service-Dogs/

Websites on Hearing Dogs for the Deaf:

- Liffey, the Hearing Service Dog blog
www.hearingdogs.org.uk/dog-blog.php

- The Listen Up Web!
www.listen-up.org/htm2/dogs.htm
- Clyde's Hearing Dog Page
www.geocities.com/grendelette/hearingdog.html

Telephones

- "Telecoils as Assistive Listening Devices (ALDs) by Mark Ross, Ph.D.
www.hearingresearch.org/Dr.Ross/telecoil_as_ALS.htm

Videophones

- Sorenson (VP-200)
www.sorensonvrs.com/apply/vp200.php
- D-Link (DVC-1000 & DVC-2000)
www.dlink.com/products/category.asp?cid=40&sec=1
- Ojo Personal Video Phone
www.ojophone.com/products
- SightSpeed Video Phone
www.sightspeed.com/
- Packet8 DV326 VideoPhone
www.packet8.net/equipment/residential/videophones.aspx
- Microsoft NetMeeting
www.microsoft.com/windows/netmeeting/

Mobile Telephones

- ATIS (Alliance for Telecommunications Industry Solutions brochures for consumers on HAC compatibility and phone labeling
www.atis.org/hac/haclinks.asp

- “Cell Phones and Hearing Aids” by Linda Kozma-Spytek, 2003
www.healthyhearing.com/library/ate_content.asp?question_id=138
- “Digital Cell Phones and Hearing Aids Frequently Asked Questions” by Linda Kozma-Spytek, Gallaudet Univ. Technology Access Program, 2003
tap.gallaudet.edu/Voice/DigitalCellFAQ.asp
- “Does Your Phone Speak QWERTY?” by Scott Mace, PC World, September 3, 2004
www.pcworld.com/printable/article/id,117648/printable.html
- “Finding Hearing Aid Compatible Cell Phones” by Neil Bauman, Ph.D.
www.hearinglosshelp.com/articles/hacphones.htm
- “Hearing Aid Compatibility for Digital Wireless Phones” by Linda Kozma-Spytek, 2006.
www.audiologyonline.com/articles/article_detail.asp?article_id=1701
- “The Mobile Phone Challenge” by David Copithorne
[/www.healthyhearing.com/library/article_content.asp?article_id=726](http://www.healthyhearing.com/library/article_content.asp?article_id=726)
- “Why Don’t Cell Phones Work With Hearing Aids?” by Beth J. Wilson
www.geocities.com/Heartland/Prairie/4727/bbhcellemi.htm?200715

Bluetooth

- “How Bluetooth Works” by Julia Layton and Curt Franklin
www.howstuffworks.com/bluetooth.htm
- ELI DirX information and list of Bluetooth cell phones
www.elihearing.com/United StatesENG/Docs/Pairing.htm

Alternate Methods of Communication

Ubi Duo

- "Deaf people get communication freedom with 'Ubi Duo,'" June 21, 2006
www.4hearingloss.com/archives/2006/06/deaf_people_get.html
- Manufacturer's website
www.sCommonline.com

Speak 'n Read (SNR)

- Manufacturer's website
www.medbio.com

Sigtel

- Manufacturer's website
www.sigtelinc.com

Television: Captioning

- "Closed Captioning FAQ" by Gary Robson, 2000-2001. Dated but informative.
www.robson.org/capfaq
- "Closed Captioning: FCC Consumer Facts"
www.fcc.gov/cgb/consumerfacts/closedcaption.html
- National Captioning Institute
www.ncicap.org/
- National Center for Accessible mMedia (NCAM)
www.ncam.wgbh.org/
- "What is the difference between open and closed captioning?"
www.washington.edu/accessit/articles?50

DTV Day Is Coming

- tv.about.com/od/hdtv/a/DTVboxprogram.htm?p=1

Chapter 7: Auxiliary Services**Distinctive Ring Service**

- Call Management Products Inc. (RingRite+)
www.callmgmtprod.com/prod02.htm
- Command Communications (ComSwitch)
www.command-comm.com
- DEAFWorks (TTYSCREENER)
www.deafworks.com
- Higgins International (FaxSwitch)
www.faxswitch.com

Telecommunications

- **A New Civil Right: Telecommunications Equality for Deaf and Hard of Hearing Americans** by Karen Peltz Strauss, Gallaudet University Press, 2006.

IP Relay

- IP Relay Service Information
www.fcc.gov/cgb/consumerfacts/iprelay.html
- IP-Relay
[/www.ip-relay.com/index.html](http://www.ip-relay.com/index.html)
- Hamilton Internet Relay
www.hamiltonrelay.com/internetrelay/index.htm
- AT&T Internet Relay
www.consumer.att.com/relay/

- Sprint IP Relay
www.sprint.com/business/products/products/wirelessRelayServices_tabA.html

Wireless Relay

- Wireless IP-Relay
www.ip-relay.com/wireless.html
- Hamilton Wireless Relay
www.hamiltonrelay.com/wireless/index.htm
- Sprint IP Wireless
www.sprint.com/business/products/products/relayDownloads_tabA.html

Video Relay Services

- Sorenson VRS
www.sorensonvrs.com/
- CSDVRS
www.csdvrs.com/service/vrs.aspx
- IP-Relay VRS
www.ip-vrs.com/
- Hands On VRS
www.hovrs.com
- Hamilton Video Relay
www.hamiltonrelay.com/videorelay/videophone.htm
- Sprint VRS
www.sprintvrs.com/

CapTel

- Ultratec (CapTel)
www.captionedtelephone.com

Short Message Service

- “Introduction to SMS” by Chris Tull archive.devx.com/wireless/articles/SMS/SMSIntro.asp
- www.gsmworld.com/services/messaging.shtml

CART Service

- “Getting the CART Rolling” by Gary Robson (1999). Classic article for prospective CART providers. captioning.robson.org/articles/captioncart/captioncart9904.html
- Communication Access Information Center
www.cartinfo.org
- “Remote CART - the User's Perspective”
www.hearinglossweb.com/res/hlorg/alda/cn/2003/remote_cart.htm
- Check the MCDHH website, www.mass.gov/mcdhh for info about CART and an application form and rate chart for CART service

Deaf-Talk

- DT Interpreting (A interpreting service organization implementing Deaf-Talk)
www.deaf-talk.com

- "Sony-DeafTalk System Boosts Hospital Communications" by InfoComm
www.livefrominfocomm.com/articles/publish/article_613.shtml
- Check for updates on Mass. Hospitals at www.disabilityinfo.org/MNIP/MCR/IR/deafHoH.asp_

Note-Takers and Computer-assisted Note-taking and C-Print

- Contact the National Technical Institute for the Deaf (NTID) for a listing of reprints available from the NTID Tutor/Notetaker Program. They also sell special multi-carbon paper sets. The Alexander Graham Bell Association publishes a training guide for notetakers and a manager's guide.

Chapter 8: Helping Yourself

Relax

- "The Fatigue Factor: How I Learned to Love Power Naps, Meditation, and Other Tricks to Cope With Hearing-Loss Exhaustion" by David Copithorne
www.healthyhearing.com/library/article_content.asp?article_id=729
- Kimberly Grebert, LICSW
Counseling Associates, 45 Lyman St., Westborough, MA 01581

Become an advocate

- Disability Policy Consortium, Inc.
P.O. Box 77
Boston, MA 02133
www.dpcma.org

Find new activities and interests**VSAM**

- VSA arts of Massachusetts
China Trade Center,
2 Boylston Street, 2nd floor
Boston, MA 02116
617/350-7713 (v)
617/350-6836 (tty)
617/482-4298 (fax)
617/350-6535 (vp)
www.vsamass.org

Deaf and Hard of Hearing Film Club

- Deaf and Hard of Hearing Film Club
Coolidge Corner Theatre
290 Harvard St.
Brookline MA 02446
www.coolidge.org/hearing

Insight Cinemas (open captioning)

- Insight Cinemas
www.insightcinema.org

MoPix Update

- Subscribe at ncam.wgbh.org/maillinglist.html
Add Mary's address to your address book or safe sender
list: mary_watkins@wgbh.org

Rear Window Captioning

The following theaters are equipped with Rear Window Captioning:

- AMC Boston Common 19
175 Tremont Street
Boston
617/423-5801
- AMC Framingham 16
22 Flutie Pass
Framingham
508/875-6237
- AMC Methuen 20 - Coming Soon!
90 Pleasant Valley Street
Methuen
978/738-8942
- Massachusetts Institute of Technology/MIT
Memorial Drive
Cambridge
617/253-3791
- Museum of Science
Science Park
Boston
617/723-2500 (v)
617/589-0417 (tty)
- National Amusements Blackstone Valley 14 Cinema de Lux
70 Worcester Providence Turnpike
Millbury
508/865-7184
- National Amusements Showcase Cinema Revere
565 Squire Road
Revere
781/284-5700

- National Amusements Showcase Cinema Worcester North
135 Brooks Street
Worcester
508/852-2944
- National Amusements Showcase Cinemas Lowell
32 Reiss Avenue
Lowell
978/551-0060
- National Amusements Showcase Cinemas Randolph
73 Mazzeo Drive
Randolph
718/963-0769
- National Amusements Showcase Cinemas West Springfield
864 Riverdale Road
West Springfield
413/733-8311
- Regal Fenway Stadium 13
201 Brookline Avenue
Boston
617/424-6111

Coalition for Movie Captioning (CMC)

- Coalition for Movie Captioning
www.nad.org/movietheatercaptioning

Mass_Deaf-Terp (One List)

- You can join Mass_Deaf-Terp, through the Yahoo Groups
at groups.yahoo.com/
and sign up Mass_Deaf-Terp@groups.yahoo.com

Chapter 9: Real Life Coping

Travel

- Contact Jonathan O'Dell at the CATTS Dept. at MCDHH
- "Travel Tips for HoH" by Beth Wilson (presented at the 1998 SHHH Convention)
www.geocities.com/Heartland/Prairie/4727/bbhtrav.htm

ADA

- **Communication Access for Persons with Hearing Loss: Compliance with the ADA** by Mark Ross, Ph.D. (York Press, Inc.)
- **A Guide to Disability Rights Law**, 2005
www.usdoj.gov/crt/ada/cguide.htm
- **Legal Rights: The Guide for Deaf and Hard of Hearing People**, National Center for Law and Deafness National Association of the Deaf (NAD), 5th ed., Gallaudet University Press
- ADA Information Services
www.usdoj.gov/crt/ada/agency.htm
- Questions and Answers
www.usdoj.gov/crt/ada/q%26aeng02.htm
- Call MCDHH or a DHILS Program.

Chapter 10: Emergency Preparedness

- “An ADA Guide for Local Government: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities”
www.ada.gov/emergencyprepguide.htm
- “Disaster Preparedness and the Deaf Community” by American Red Cross, Rochester chapter, and NTID (National Technical Institute for the Deaf) at Rochester Institute of Technology
www.rochesterredcross.org/Data/FileManager/Deaf%20Preparedness%20Brochure1.pdf
- “Emergency Preparedness and Emergency Communication Access” by Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN) and Northern Virginia Resource Center for Deaf and Hard of Hearing Persons (NVRC), 2004
www.nvrc.org/content.aspx?page=5138§ion=5
- “Emergency Resource Guide,” Washington Military Dept. and Washington State Dept. of Health, 2007
www.doh.wa.gov/phepr/handbook/hbk_pdf/Emer_Res_Guide07.pdf
- “Personal Emergency Preparedness Plan,” Disability Policy Consortium
www.dpcma.org, select Emergency Preparedness from list at left of screen
- Department of Homeland Security website
www.ready.gov
- Community Emergency Preparedness Information Network (CEPIN) website
www.cepintdi.org/

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